NEW MEXICAN HISPANIC LATINOS' PERSPECTIVES ON CANCER PAIN: MEANING, COPING, AND BARRIERS TO RELIEF

by

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ABSTRACT

The primary aim of this qualitative descriptive study was to explore the experience of cancer-related pain (CRP) among Hispanic/Latino adults in New Mexico, and secondarily to describe how institutional and provider-level factors influence the personal experience of CRP. Fourteen individual interviews were recorded and independently transcribed. To triangulate findings additional data came from interviews with two allopathic physicians, a traditional folk healer (curandera), and three family caregivers; medical records were reviewed for evidence of pain assessment and management. Thematic analysis guided the formation of three primary themes and associated categories. *Pain Is More Than Physical* captured aspects of pain beyond a physical experience, including meaning, ways pain was described and the critical need for building trusting relationships with providers. *Coping with Pain* encompassed participants' strategies for managing pain, inclusive of culturally-learned behaviors. Of importance was family support and faith in dealing with pain. The theme, *Hurdles and Hindrances*, reflected barriers to pain relief. Gaps in pain assessment and challenges related to accountability for who was managing the pain were identified. Deficits in provider communication and being treated with respect were described. A final element to this theme reflected misconceptions and medication side effect management. Medical record analysis found limited use of evidence-based guidelines in pain assessment and management. Participants suggested that providers situate pain within the context of the

whole person and family experience and strive for better patient-provider communication. Family members described needing to advocate for their loved ones, reinforcing the challenges with pain assessment and management described by participants. These findings align with past research and suggest a shift in the provider-centric paradigm, instead creating a patient/family centered model. Greater inclusivity supports development of a trusting provider/patient/family triad. Improving communication creates a platform for a better understanding of the patient/family experience and how behavior and coping is shaped by culture, thus informing management and the quality of care. Further recommendations for professionals and institutions are developing clearer accountability for pain management as patients' transition between specialist-providers, as well as creating a stronger infrastructure to support communication and delivery of evidence-based practices and quality metrics to evaluate pain care.

I wish to thank all of the participants for willingly sharing their stories as well as the families who supported their loved ones. I hope to have captured your experiences in a way that honors you and improves the quality of care others receive. I also cannot thank my family and friends enough for the ongoing, steadfast presence, patience and support, particularly my daughter Aleya.

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CHAPTER I

INTRODUCTION

There are few generalizations that can be made about cancer and its associated experiences, yet some commonly occurring symptoms can be linked with cancer and its treatment: Pain remains a leader among them. Despite advances in pain management made over the last 15-20 years, moderate to severe pain persists among people with cancer. (McGuire, 2004; van de Beuken-van Everdingen, Rijke, Schouten, Kleof, & Patijn, 2007). Research on cancer pain continues to generate changes in public understanding, professional practice, and policy. In spite of expanding treatment options, increasing knowledge about pain physiology, professional educational efforts, and the dissemination of national and international professional treatment guidelines, many persons with cancer continue to experience unacceptable levels of pain (Paice & Von Roenn, 2014; van de Beuken-van Everdingen et al.). Goodwin and colleagues recently acknowledge that in spite of such efforts, little improvement has been realized in the last decade (Goodwin, Bruera, & Stockler, 2014).

When persons are hindered by pain the ramifications extend beyond the individual. Undertreatment of cancer-related pain (CRP) negatively impacts many domains of life, often affecting families, communities, and society. Studies have documented the cost to society and health care systems of unrelieved pain in terms of lost

productivity, increased hospital lengths of stay, untimely readmissions, and frequent visits to outpatient centers and emergency rooms (Berger et al., 2003; Dagenais, Caro, & Haldeman, 2008; Edelsberg & Oster, 2007; Ferrell, 1983, 1995; Ferrell & Griffith, 1994).

Pain as a physiological sensation does not occur in isolation of meaning – it is embedded socially, culturally, spiritually, and economically. Disparities in treating CRP among minority populations potentially compound the experience of pain and distress (Anderson et al., 2004).

This chapter introduces the purpose and specific aims of this study, then provides an overview of the scope of the CRP problem. Undertreatment of CRP and how it is particularly pronounced for persons of diverse populations, including Hispanic/Latinos is reviewed. The summary and statement of the problem, introducing the study, conclude the chapter.

Purpose and Specific Aims of This Study

Understanding how CRP meaning is generated and experienced among Hispanic/Latinos has received limited exploration. The purpose of this descriptive qualitative study was to explore how Hispanics/Latinos living in New Mexico experience CRP in their daily lives and how these individual experiences are influenced by culture, local social/environmental, healthcare structural and provider-level factors.

Specific Aims and Coinciding Research Questions

Aim 1

Explore dimensions of the CRP experience as these are described by Hispanics/Latino participants.

RQ1: *What characterizes the experience of CRP among New Mexican Hispanics/Latinos?*

Aim 2

Describe participants' perspectives of how local, institutional, and provider-level factors influence the experience of CRP.

RQ2: *What external factors influence the experience of living with CRP among New Mexican Hispanics/Latinos?*

Contextual Background

Cancer-Related Pain: Prevalence and Defining

Pain and cancer pain specifically has been considered a national patient care priority. In 1994, the Agency for Health Care Policy and Research (AHRQ – formerly AHCPR) issued a practice guideline specifically addressing the assessment and management of cancer-related pain to assist providers, policy-makers and the public to better understand and treat this phenomenon. Pain advocacy groups, both lay and professional, have raised awareness about cancer pain management by creating professional and lay organizations for the management of pain, developing professional position statements and national guidelines for assessment and treatment, implementing accreditation criteria related to the assessment and treatment of pain and finally, establishing grassroots advocacy groups – all important steps (American Cancer Society (ACS), 2014; American Pain Society (APS), 2014; International Association for the Study of Pain (IASP), 2014; Joint Commission for Accreditation of Hospital

Organizations (JCAHO), 2014; Oncology Nursing Society (ONS), 2014; National Comprehensive Cancer Network (NCCN), 2014).

Estimates of new cancer cases in the US for 2014 will exceed 1.6 million and cancer deaths are predicted to reach 585,720 (ACS, 2014). The majority of persons with cancer will experience some degree of pain during active cancer treatment and into the ensuing years. Although methodology for determining prevalence figures has come under scrutiny, the fact that pain is commonly associated with a diagnosis of cancer cannot be overemphasized (IOM, 2011; National Institutes of Health State-of-the-Science Panel, 2003).

Estimates place the prevalence of cancer-related pain from 14-100% (ACS, 2000; Brescia, Portenoy, Ryan, Krasnoff, & Gray, 1992; McGuire, 2004; van den Beuken-van Everdingenk et al., 2007). Incidence of CRP has been described along the care continuum, occurring in 59% of individuals receiving active cancer treatment and 64% of those with advanced disease. Prevalence of CRP was captured in a study conducted by the Eastern Cooperative Oncology Group (ECOG) using a sample of 1308 cancer patients. Sixty-seven percent reported they had recently experienced pain, and of those with pain 36% described that pain as bad enough to impair function (Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997). Similar findings continue in more recent reports, reflecting impaired functionality (Deandrea, Montanari, Moja, & Apolone, 2008; Kwon, 2014).

People with cancer are surviving longer, with 5-year relative survival rates estimated to be 68% overall for those diagnosed between 2003-2009 (ACS). Recent reports estimate that 5-10% of survivors have lingering chronic pain capable of

interfering with daily life (Glare et al., 2014). Pain in cancer survivors is complex as it may be related to late effects of treatment and can be associated with multiple symptoms (van den Beuken-van Everdinger, 2012). The scope of CRP care has expanded to include people in all stages of cancer diagnosis, treatment, and survival and at the end of life (National Institutes of Health (NIH) State-of-the-Science Panel, 2003).

Defining Pain

Defining the elusive concept of pain has most often centered on the inherently subjective and individual level factors. From Aristotle to contemporary times, many have cast their own interpretation of such an experience, trying to quantify it as well as acknowledge the many complexities that influence the pain experience (Montes-Sandoval, 1999). Morris (1991) reminds that pain is constructed differently depending on language of origin. Some emphasize the somatic while others see no separation between physical and mental (p. 15). Morris suggests that the challenge in defining pain is rooted in the assumption that it is a singular cohesive entity. The goal is not to isolate a discreet definition but rather describe the dynamic features that are affiliated with pain. Within these features, Montes-Sandoval has included physical, social, cultural, subjective, describable and indescribable and entangled with other sensations such as anxiety and distress. The scientific community recognized the need for a unified taxonomy across disciplines to enable scientific inquiry, advancement and exchange of information. Working definitions that most disciplines could agree upon emerged.

A classic and widely accepted definition comes from the International Association for the Study of Pain (IASP) which states that pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in

terms of such damage" (Merkey & Bogduk, 1994, p. 210). This definition captures the physiological aspects of the experience as well as some of the affective sphere. The major assumption of this definition is that pain is fundamentally a physiological experience, keeping the less measurable and obscure aspects unacknowledged. IASP concedes 'psychological' features but goes little further to elaborate. It should be acknowledged however that the notion of 'sensation' is represented as 'experience' in their definition, easing the emphasis on corporal features.

Another commonly referenced working definition comes from Margo McCaffery (1980) stating, "pain is whatever the experiencing person says it is, existing whenever he says it does" (p. 26). McCaffery's definition is highly subjective yet remains free of attachment to physical, emotional or other particular domains. Her construct of pain allows for individuals to frame pain in whatever way resonates in their life.

Finally, Mahon (1994) gleaned four attributes for a general concept of pain using a phenomenological framework. These domains are: a personal experience; an unpleasant experience; a dominating force; and endless in nature. Mahon's attributes primarily focus on the individual experience of pain, not recognizing external aspects that can get entangled with this subjective experience called pain.

These conceptualizations of pain while epistemologically grounded in physiology, privilege the central lens of perception on individual experience and as IASP acknowledge need not include measurable evidence of tissue damage to exist. What is lacking among all definitions is recognition of cultural, local, situational, and provider-level aspects of making sense of a painful experience; considerations that may be at the core of one's experience. Morris (1991) proposed decades ago that it was futile to try

and unmask a perfect definition of pain and rather such efforts should be suspended and replaced with "ordinary language, common usage, and everyday experience" (p. 16).

McCaffery's definition, being the one that does not create a limited construction of experience, was used to reference pain in persons with cancer in this study. Understanding both physical and affective domains of pain are important and there are unique features of both in CRP that distinguish it from pain of a nonmalignant origin. A broad overview of both physiological and affective dimensions is presented below.

The Many Domains of Pain

Physical Dimensions

CRP has been divided into three major categories: pain caused by the tumor; pain stemming from its treatment (including surgery, radiation, or chemotherapy) or side effects; and pain unrelated to either (NCCN, 2014). Cancer pain can come as a sign of a new or recurrent malignancy (Caraceni & Portenoy, 1999; Cleeland, 1984). Although intensity varies based on pathophysiology, CRP consistently appears to primarily stem from tumor invasion (Caraceni & Portenoy; Cleeland). Caraceni and Portenoy facilitated a large international study in 24 countries, comprised of over 1,000 persons experiencing CRP requiring opioids as part of the treatment. They categorized the pain experiences into various pathophysiological origins. The majority of CRP in this sample stemmed from the underlying neoplasm (92.5%). The authors defined nociceptive pain as pain related to tissue injury, somatic or visceral in nature and neuropathic pain was felt to originate from neural tissue damage. As demonstrated, the majority of CRP does come from nociceptive pain, a type of pain more amenable to intervention; however, there is a significant percentage that is mixed or primarily neuropathic in origin. In addition,

Caraceni and Portenoy highlight the complexity of cancer pain syndromes. Table 1 summarizes pain syndromes associated with the original cause and type of pain. As they demonstrate, the majority of cancer pain syndromes are related to direct tumor involvement with resulting nociceptive pain.

A comprehensive assessment of CRP must include an understanding of the essential physical origins of pain. In order to do this kind of proficient and complete assessment, clinicians must understand the research evidence on the complex nature and domains of CRP.

Philosophical and Epistemological Dimensions

Attempts to understand pain as a social construct precede modern times. Early philosophers such as Aristotle, Plato, and Descartes had much to say about pain, although from different perspectives (Duncan, 2000). Research in the last few decades has attempted to unravel and explain pain often from an objectivist epistemological vantage (Curtis, Krech, & Walsh, 1991; Dodd, Du Pen, Du Pen, Polissar, Hansberry, Kraybill, Stillman et al. 1999; Janson, Facione, Faucett, Froelicher, Humphreys et al., 2001; McCaffery & Pasero, 1999; Wool & Mor, 2005). These works, largely of a positivist nature, have sought to describe, quantify, justify, and control the construct of pain (Crotty, 1998). Indisputably this work has been of great significance in furthering the understanding and management of cancer-related pain. Pain has been viewed as an isolated experience as well as described as an interdependent relationship between both the psychic and physical worlds (Duncan, 2000).

Despite the advances in formalizing pain care and its influence on public health, our "techno-centric" and instrumental approach has not been sufficient in addressing the

Table 1

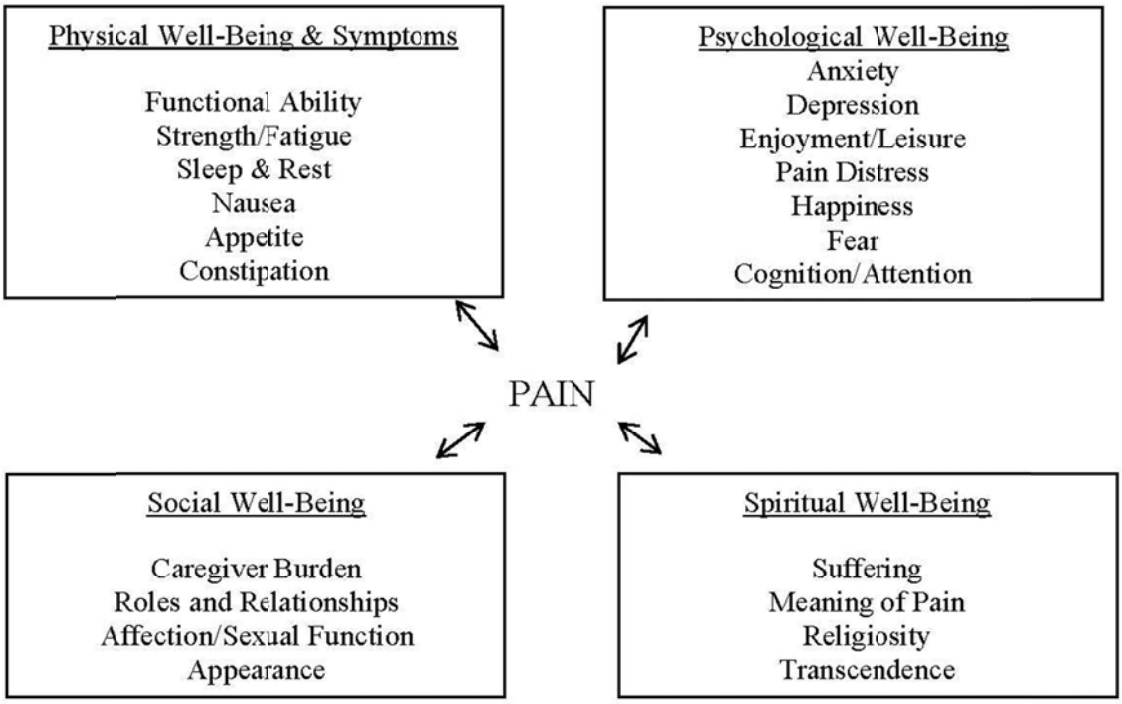
Cancer Pain Syndromes

Cancer Pain Syndrome/Origin	% Of Total Cases*
Related to direct tumor involving somatic or visceral tissue (*Nociceptive*)	98.1
Related to direct tumor involving lesions of nervous tissue (*Neuropathic*)	27.8
Related to therapy (*Mixed*)	10.2
Unrelated to cancer or treatment	6.6
* Some have more than one	Adapted from Caraceni & Portenoy, 1999

complex phenomenon of pain; it is simply more than a physio-sensory happening. It is experienced at a physical level but also affectively, cognitively, socially, spiritually, within community and systems of care.

Research has linked poor pain control to many other aspects of life and living; such as appetite, enjoyment in life, functional level or activity, intensity of other symptoms, immune function, depression, sleep, fatigue and anxiety (Cleeland, 2007; Juarez et al., 1998; Paice & Ferrell, 2011). Various levels of interplay exist between all these spheres of influence. Padilla and colleagues (Padilla, Ferrell, Grant, & Rhiner, 1990) have proposed a global and multidimensional model for the pain experience, inclusive of physical well-being but also other domains of quality of life - psychosocial or interpersonal wellbeing; spiritual and social well-being. Their framework has expanded how practitioners approach pain care (Figure 1).

This model envelops many of the core complexities of a CRP experience. Physical well-being includes many bodily aspects of comfort, such as one's ability to sleep and eat. The psychological and spiritual domains bundle the deeply personal, often private, yet universal components of one's life.



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ved from City of Hope Pain & Palliativ
http://prc.coh.org/qual_life.asp

Social well-being recognizes the outward connections in an individual's world that are impacted by pain. What is not acknowledged in this model is the interplay of CRP and macro level structures like health care organizations and providers, local influences, and cultural orientations to the experience of living with pain.

Barriers and Undertreatment

An important assumption embedded in traditional definitions of pain is that the most reliable report of the existence of a painful experience comes from the person having the pain. Not accepting the patient's report of pain is a common first area of misunderstanding resulting often in suboptimal pain management (Kwon, 2014). There are many contributing factors to the undertreatment of pain, including barriers

encountered by providers, patients, family, institutions, and society in identifying pain characteristics and employing and evaluating pain treatments (Kwon; Paice & Ferrell, 2011). The pain experience is particularly entwined with the patient/family-situated cultural dynamics that enable or constrain how individuals identify pain, imbue pain with meaning and how and when pain expression or stoicism is expected (Cleeland, 1984). Not to be neglected is the interaction of the patient and healthcare provider as contributing to potential undertreatment (Kwon). All of these factors can serve to create misunderstandings, barriers, and ultimately undertreatment of pain when the patient and his or her culturally-situated pain experience is disclosed to biomedical clinicians who may not have the same understanding of pain as their patients.

Disparities in Pain for People with Cancer

Defining disparities in pain care has received recent attention. Both Braveman (2006) and Fink (2009) have taken a comprehensive look at the discourse around disparities and health inequities. Truman and colleagues (2011) cite the literature as it has differentiated disparities from inequalities and inequities as a component of in equalities. They describe disparities as differences in health outcomes based on social, demographic, environmental or geographical factors. Inequalities are a measure of population health based on particular attributes such as race/ethnicity, education and income. Inequities, considered unethical represents a modifiable element of inequalities based on social standing. The National Cancer Institute (NCI) (2013b) defines cancer disparities as "differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States" (p. 1). The Health and Human Services (HHS) department describes health

disparities as differences in health outcomes between populations that may be closely linked with social, economic, and environmental disadvantage that are often driven by the social conditions in which individuals live, learn, work and play (2011, p. 1). Race, ethnicity, gender, gender identity, age, disability, socioeconomic status and geography are examples of factors that contribute to one's ability to achieve health (HHS, 2014).

The Agency for Health Quality and Research (AHRQ) states that pain not only adds to the burdensome experience of cancer but that this burden is likely heavier for minorities, women and the elderly, as those groups are often undertreated for pain (2001). Hispanic/Latinos represent one such group and are at risk for greater disparity in management of CRP. The literature reports evidence of greater reporting of pain and higher levels of associated distress among Hispanics (Anderson et al., 2002; Cleeland et al., 1994; Im, Guevara, & Chee, 2007; Ng et al., 1996; Todd, Samarro, & Hoffman, 1993). Poorer outcomes in many domains, including quality of life have also been reported in Hispanics when compared to other groups (Green et al., 2003; Juarez, Ferrell, & Borneman, 1999).

The US Census Report (2011) reports more than half of the growth in the US population was accounted for by the Hispanic population, rising from 13% to 16% between 2000 and 2010. There is an imperative to more intentionally explore cultural influences in symptom experiences and health care disparities in order to better inform intervention strategies that are more attuned to patients' needs and desires, more humane, and more effective in relieving suffering.

Addressing health disparity and quality of life issues are part of Healthy People 2020 goals and eliminating such disparities is a federal health promotion and disease

prevention agenda priority (National Center for Health Statistics, 2012). The Oncology Nursing Society, National Institutes of Health, American Cancer Society, and Institutes of Medicine have all targeted cancer symptoms as well as health disparities as major focus areas for their respective research agendas (ACS CAN, 2007; IOM, 2011; NIH State-of-the-Science Panel, 2003; ONS, 2006).

Statement of the Problem

Undertreatment of cancer-related pain is complex and multifaceted. Forces at work at the individual, provider, institution and societal levels converge as they contribute to CRP (Hui & Bruera, 2014; Kwon, 2014). Additional contributing factors include the cultural context and meaning of pain, barriers to pain relief, cultural beliefs about pain, and shared expectations about pain expression that are seldom acknowledged or explored in clinical encounters (Anderson et al., 2004; Bates, Edwards, & Anderson, 1993; Campbell et al., 2009; Green et al., 2003; Im, Guevara, & Chee, 2007; Juarez, 1996; Juarez et al., 1998). These realities have only modestly shifted over the past 20-30 years (Goodwin, Bruera, & Stockler, 2014).

Little research has explored dimensions of CRP among New Mexican Hispanic/Latinos as a cultural group and factors that intersect with these experiences. The general discourse found in medical-professional-bureaucratic initiatives and directives have targeted a more diagnostic-disease framework for addressing gaps in pain care. What is missing is an examination of the human experience and how structural influences, power and biases contribute, in an effort to activate change and improve outcomes. Describing these factors within the context of culture promotes a patient-

centered holistic approach to care and a shift in provider interventions to achieve greater relief of CRP among Hispanic/Latinos.

Pain could be considered a cultural event and studied from such a perspective (Alrich & Eccleston, 2000). This standpoint is meant to suggest that the many unique individual-level factors, including upbringing, and culture of origin as well as local culture, biological function and dysfunction, interactions with the health care system are part of experience. In order to explore this experience from the position of the individual with pain, a qualitative descriptive approach guided this study. All such influences will be addressed as they arise through various avenues of data collection; including personal, cultural and factors of power and positionality.

Summary

This chapter has outlined the purpose and specific aims of this research study and briefly defined CRP, summarizing prevalence among those with a cancer diagnosis. Undertreatment of pain continues in spite of advances in treatment, professional education, and development of management guidelines and professional position statements. Racial and ethnic groups as a subset of those with CRP are disadvantaged and receive poorer pain care.

We must be willing to look thoughtfully at the complexities of this problem. The discourse addressing interactions between the physiologic, emotional, and social aspects of pain is well established. Medical care nonetheless has privileged the biological basis for pain. This study proposed a reconstructed review of pain as a truly whole-person event that occurs within a particular cultural setting, recognizing that elements of experience are situated within a local climate of provider and system factors that *also*

influence pain.

David Morris (1991) challenged the Western technocratic frame of understanding pain. Rather than suggesting pain be untangled from what science has discovered of its physical roots, instead we gather "together from episodes scattered throughout human history, across cultures and across time" to reframe that experience (p. 2). He further suggests the larger social and medical environments have culturally-constructed what pain is to modern society.

This research is guided by the assumption that pain experiences are influenced by multiple facets of engagement and meaning, and I invite such consideration. Experience of pain and thus understanding it requires a deeper exploration, inclusive of physical manifestation and expression, emotional ramifications, and culture as well as factors external but influential to the individual sphere, such as the healthcare system and provider-level factors.

Chapter II expands on the current state of knowledge related to CRP among Hispanic/Latinos. The chapter first looks at broad categories of pain care, including assessment, education, and treatment. The nearly unwavering issue of undertreatment of CRP is summarized with a review of individual, provider and structural contributions. Secondly, Chapter II addresses Hispanic/Latinos and health, starting by reviewing the definition of Hispanic and current census data, health care research pertaining to CRP in this population and finally, summarizing Hispanic health outcomes. The final section of Chapter II narrows on CRP specifically in Hispanic/Latinos and data on undertreatment. Literature relevant to cultural influences and meaning of pain is also reported.

Chapter III outlines the study design, including description of the methods and rationale use to study CRP. A description of the sample and a description of the data collection methods and steps are included. Samples of questions used to guide the interviews as they align with the research aims are included. A summary of the steps in data analysis and software utilization follows. All sources of data used in the analysis including primary participant interviews, provider interviews, caregiver contributions, medical record reviews and finally field notes are described.

Chapter IV is a synthesis of results from analysis, situated in alignment with the study aims. Three themes and 11 associated categories are reported with transcript examples from interviews used to demonstrate credibility and add a vivid richness to the text. Chapter V discusses findings, highlighting implications and application of findings for practice, education, research and policy.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter provides a synthesis of the state of knowledge in two bodies of literature, proceeding along parallel yet seemingly unrelated paths. An overview of cancer pain treatment and undertreatment (Part I) is followed by an appraisal of Hispanic/Latino demographics and health outcomes research in this population (Part II). These two domains intersect for a review of the current relevant science addressing cancer-related pain (CRP) among Hispanics (Part III); describing disparities in treating CRP in this population. The chapter summary articulates gaps that provided the foundation for the current study's scientific exploration of the experience of CRP among New Mexican Hispanic/Latinos.

Part I: Review of Cancer Pain Treatment

An overview of types of CRP was provided in Chapter I and will not be repeated here. It is important in understanding the experience of CRP among Hispanics to situate such exploration within the context of what are well-established and growing bodies of evidence available to guide practitioners in *managing* CRP. National and professional guidelines have been crafted summarizing the state of knowledge around best practice for addressing CRP and strategies to guide systems in monitoring pain-related outcomes

(Agency for Healthcare Research and Quality, 2001; Gordon et al., 2005; JCAHO, 2000; National Comprehensive Cancer Network, 2009; Oncology Nursing Society, 2008).

Initial efforts came from the Agency for Health Care Policy and Research (now known as the Agency for Healthcare Research and Quality – AHRQ) in the early 1990s with published practice guidelines for managing acute pain and a separate guideline for cancer-related pain. These references are now archived and not recommended for practice as knowledge has advanced and the guidelines no longer represent current evidence-based practice. More recent guidelines have been grounded in the evidence, demonstrating best practice (Abu-Saad, 2006; APS, 2014; NCCN, 2014; ONS, 2014).

All of the pain guidelines and recommendations for practice make the following assumptions, that the majority of CRP is treatable with noninvasive measures; interventions are directed by acceptance of the individual report of pain; acknowledgement that pain is multidimensional; and finally, that providers are accountable to address such pain as part of routine care (Paice & Ferrell, 2011). This discussion provides a synthesis of these guidelines and is organized to address assessment, interventions, measuring outcomes and institutional accountability.

Assessment and Education

Health care providers should assess patients' CRP and treat it promptly. This requires regular and ongoing assessment. In a recent review, Kwon (2014) reported that pain assessment is the cornerstone to intervention and that providers admit it is the weak link in pain care.

The initial assessment is the most comprehensive, including all of the elements outlined in Table 2.

Table 2

Summary of Pain Guidelines and Practice

Assessment	Education	Treatment	Institutional Accountability
Patient Experience: Initial Assessment • Intensity • Location • Quality • History of Pain-timing, onset, • Aggravating Factors • Alleviating Factors • Medication Regimen • Patient goals re: pain care • Interference with activities • Other symptoms • Physical Exam • Response to therapy • Relief • Prior Therapy • Meaning/ Consequence for patient/family • Cultural beliefs • Spiritual religious considerations • Psychological • Medical/Diagnostic • Etiology/ Pathophysiology Ongoing Assessment • Comprehensive at 24 hours after new plan implemented; • Ongoing based on analgesic effect Frequency of dose titration. • Adjustment of plan based on reassessment	• Reassure pt/family that most of pain can be relieved safely and effectively. • Pt/Family part of pain plan of care and active participants in management • Ongoing professional education in pain assessment & management • Continual processes with focused education as treatment plan changes or is modified • Continual improvement and reestablishment of patient goals.	Multimodal Approaches • Pharmacologic as guided by the World Health Organization Analgesic Ladder (1996) Oral route preferred • Pharmacologic interventions/Medication selection deteml ined by patient preference, pain intensity and goals of care. • Use of long acting and short acting opioids and co-analgesics Safe Handling • Attention to issues of diversion Interventional Strategies • Reserved for more complex pain syndromes. Consultation as indicated. • Epidural/Intrathecal • Regional blocks • Neuroablation • Neurostimulation • Concurrent management of opioid side effects. Physical Therapies • Physical Therapy • Orthotics • Assistive Devices Psychological Support • Integration of nonpharmacological Interventions • Cognitive/Behavioral • Evidence-based Integrative Therapies	• Assessment recorded and visible to all providers • Selected assessment tools demonstrating adequate psychometric testing • Interventions to be based on a complete/ comprehensive assessment of multiple domains of the pain experience – physical and emotional. • Interventions based not only on intensity report but appropriate to type of pain and treatment setting • Standardized documentation format and assessment measurement • Evidence of shared decision- making and individualized treatment plan • Monitoring for evidence- based pain treatment strategies • Develop and make available data from internal performance measures focused on cancer pain assessment and management.

Source: Abu-Saad, 2006; APS, 2005; NCCN, 2014; ONS, 2011; Paice & Ferrell, 2011

A complete history of the pattern, character, intensity, and location along with a medication history and identifying factors that make the pain better and /or worse are essential (WHO, 2000). Much literature exists around assessment tools particularly in how to quantify pain intensity (NCCN, 2014).

Patients and caregivers are considered key members of the treatment team, customizing interventions based on their values and beliefs (Gordon et al., 2005). Educational efforts include a review of common misconceptions about pain, including fear of addiction, assessment of barriers and referral to appropriate resources, again recognizing the impact of pain on many domains (Lovell et al., 2014; Padilla, Ferrell, Grant, & Rhiner, 1990). Finally patients and family members must receive information for any specific skills needed to most effectively and independently manage pain and its relief.

Guidelines and directives also target education toward professionals responsible for providing competent pain care. Curricula have been developed both for the academic settings as well as professional continuing education, with the intent of developing entry-level competence (AACN, 2010; Abu-Saad et al., 2006; IASP, 2014b).

Treatment

There are many layers of complexity surrounding appropriate treatment of CRP. The mainstay of all treatment plans begins with pharmacological therapy. Choice of analgesic, schedule, route, and dosing are based on the WHO analgesic ladder (Figure 2) as well as collaboratively identified treatment goals and the underlying disease process. Kwon (2014) reported that when implemented appropriately, the WHO ladder was effective in addressing pain from 71-100% of the time. Three broad categories of

Figure 2. World Health Organization Pain Management Ladder, 1986.

pharmacological agents are organized to address both level of pain intensity and physiological aspects of the pain itself. Nonopioid analgesics consisting of nonsteroidal anti-inflammatory agents or acetaminophen are suggested as a starting point for mild pain (NCCN, 2014; ONS, 2011). Short-acting opioids and co-analgesics may or may not be indicated for pain at this level.

Guidelines for pain of moderate and severe intensity recommend short acting opioids as the foundation of a pain regimen. Percentage of change in dosing as well as frequency of dose escalation (titration) is driven by the level of severity reported. Generally pain levels of greater than four on a 0-10 scale will yield a multimodal approach to management expanding beyond using opioids exclusively.

Augmenting opioids with co-analgesics (adjuvant agents) and nonpharmacological strategies are also designed around pathophysiology and are evidence- based (Abu-Saad, 2006; NCCN, 2014; ONS, 2011). Antidepressants and

anticonvulsants have shown benefit in treating neuropathic pain, as have topical agents such as Lidocaine patches that can access pain pathways through different mechanisms. Corticosteroids also demonstrate a synergistic effect when used with opioids (NCCN, 2014).

Pain is not treated exclusively with pharmaceutical agents and must simultaneously address other domains. Psychological support and education are paramount regardless of the pain intensity. Patients and caregivers need to be given the sense of a collaborative team approach to their experience and believe that their pain will be aggressively addressed. There is an extensive supply of nonpharmacological resources that should be considered in tandem to pharmacological ones. Simple physical positioning, use of heat and ice, and physical therapy are common examples. Additional examples demonstrating an acceptable level of evidence include psycho-educational interventions, use of acupuncture and acupressure, relaxation techniques, and distraction training (NCCN, 2014).

A final category of treatment intervention is reserved for a small segment of cancer-related pain conditions. Invasive approaches are rarely necessary but epidural or intrathecal infusions of analgesics and anesthetics for example play a critical role in relieving some of the more complex pain issues. More extreme measures include neuroablation or neurostimulation for well-localized pain and decisions regarding efficacy need to be made by experts in the field; many of these procedures have a limited role in CRP (NCCN, 2014; Paice & Ferrell, 2011).

Treatment of CRP is complex and requires rigorous assessment and rapid intervention. A collection of evidence-based therapeutic tools has existed for many years

now, assisting practitioners in both pharmaceutical and nonpharmacological methods of treating cancer-related pain. Individualized care requires an interdisciplinary team of experts from many fields with specialty knowledge and cultural sensitivity to assist those struggling with the most common cancer related-symptoms. Despite these resources barriers and misconceptions persist. Sustaining the effort of high quality competent pain care is the responsibility of individual professionals but also health care systems. Pain care is not possible without the collective efforts of healthcare systems, professionals, patients, and caregivers working together. The following section addresses the institutional responsibility and role in delivering and monitoring quality pain care.

Institutional Accountability

Standards for quality improvement and performance measures in pain care have been published to guide institutions in setting benchmarks and expectations. Systems have been developed to guide institutional accountability, to establish formal evaluation mechanisms with required indicators for accreditation, and to monitor processes within the organization (The Joint Commission, 2014). Not only are acute care settings responsible for such compliance but also long-term care, outpatient healthcare, home care, hospice and health care networks. (APS, 2005; Berry & Dahl, 2000).

The specific components of initial and ongoing assessments are also analyzed using performance indicators. Evidence of strategies for ensuring a smooth transition across health care settings in quality pain management must also be evident (APS, 2005). Table 2 has summarized indicators established to quantify method, frequency and direct accountability for assessing and documenting pain.

Again, making strides at impacting cancer-related pain requires a multilevel approach. Without systems accountability, actions at the level of the individual will be protracted. Financial gains by such progress can be measured in health care cost savings and efficiency in resource consumption (Berry & Dahl, 2000). Carefully and competently managed pain potentially reduces unnecessary readmissions, visits to emergency rooms or clinics and potentially reduces lost productivity.

As organizations were developing guidelines for pain assessment and management, various individual provider groups began to follow with their own professional position statements and claims of provider accountability; a critical step in shifting the paradigm and assuming responsibility themselves. For example, both the American Pain Society and the Oncology Nursing Society published such directives (APS, 2004; ONS, 2014). Through the development of evidence-based guidelines, professional positions, and regulatory mandates there has been an emergence of liability for undertreatment and mismanagement of pain (Frank-Stromborg & Christiansen, 2000; Warm & Weissman, 2002). Nurses, physicians, and systems have been held accountable for breeching their duty to provide pain care based on established standards resulting in harm or suffering (Berry & Dahl, 2000; Frank-Stromberg & Christianson; JCAHO, 2000; Shapiro, 1996; Valglienti & Grinberg, 2004).

As much as pain educators, practitioners, and advocates have stood up for proactive and competent pain management for persons with CRP, others raise valid concerns about how to balance safe effective care within a climate of diversion and unintentional prescription overdose. The growing use of prescription medication for recreational purposes and associated deaths have understandably caused greater scrutiny

of regulatory and policy guidelines around professional training, prescribing practices and public education (Ornstein & Weber, 2012). This coexisting and epidemic public health concern has created federal and state level investigation. The reality that drug overdose has increased by 118% from 1999 to 2011 is cause for serious reflection on opioid prescribing practices.

Those needing prescription medication for CRP are potential at risk of further undertreatment (Center for Disease Control (CDC), 2014) as providers are reluctant to prescribe opioids. Among the pharmaceutical overdoses in 2011, 74% involved opioid analgesics, mainstay agents for treating CRP (CDC). These very real events have cast a shadow of concern for equitable effective care for CRP and augmented barriers to adequate treatment.

This section has summarized treatment of CRP from various levels of influence and responsibility as described in professional guidelines and national recommendations. In spite of the scientific evidence that treatment exists to address the majority of such pain, many persons with CRP continue to be under treated or mistreated (van den Beuken-van Evergingen et al., 2007). In their systematic review these authors found that pain was not selective by cancer type. Although stage of disease did impact the prevalence of pain, type of cancer did not demonstrate appreciable differences in pain (van den Beuken-van Evergingen et al.). Having the knowledge and means clearly is not all that is needed to ensure acceptable management of CRP. Chapter I reviewed common misconceptions that fuel the undertreatment of pain. The following section describes prevalence and characteristics of undertreatment.

Review of Barriers and Undertreatment

As outlined above, CRP is prevalent across the cancer care continuum and estimates of undertreatment unfortunately persist. Reports of undertreatment have ranged from 40-50% among those with CRP (Deandrea et al., 2008; Paice & Von Roenn, 2014). Examining the prevalence of undertreatment as well as isolating predictors and risk factors is complex and multilayered. Several level factors are described as contributors to the undertreatment of pain and barriers to pain relief. These are described as they relate to individuals, providers and structural and public health factors. The following section provides a brief overview of these barriers presented as they contribute to undertreatment of CRP.

Patient Level Factors

Deandrea and colleagues (2008) conducted a systematic review of studies worldwide published between 1987-2007 examining undertreatment of CRP. Of the 26 selected studies appraised, there was a 43% mean proportion of undertreatment of CRP. These researchers further attempted to shed light on some of the predictors of undertreatment. Contrary to other studies, this systematic review concluded that age or gender does not play a consistent role across studies in predicting CRP undertreatment (Cleeland, 1994; McNeill et al., 2004). Several issues emerged as stronger determinants of undertreatment, the majority of which are related to patient demographic features:

- Geography – poorer countries fared worse;
- Socioeconomic variables – lower economic status of patients predicted greater undertreatment;

- Less ill (measured by performance status) and earlier stage of disease - reported greater undertreatment;
- Discrepancy between physician and patient estimate of pain intensity – undertreatment more prevalent;
- A noncancer specialty treatment setting – greater undertreatment

Knowledge level factors have been described to influence undertreatment. For patients there may be a lack of understanding of medication usage and misconceptions of side effects (Kwon, 2014). One may reasonably argue that these level factors, while usually affiliated with the person with CRP, may indeed be better suited as a barrier due to lack of provider-patient communication and education. In other words, people may have knowledge limitations because of poor information sharing from providers.

Challenges around communication have often been cited as barriers and sources of undertreatment (Kwon, 2014; Paice & Ferrell, 2011). Various reasons may be underlying such disparity including a desire to not distract the focus of care away from treating the cancer, language barriers, not wanting to complain, wanting to be a "good" patient, holding a fatalistic belief about pain, or not wanting to displease their provider and appear to be complaining unrealistically (Cohen et al., 2008; Kwon; McNeill et al., 2003; Paice & Von Roenn, 2014). Discrepancy between provider and patient estimate of pain, access to specialty care and lower economic status might be indirectly linked to communication, language and culture. Deandrea et al. (2008) did not pursue such an analysis in their review.

McNeil and colleagues (2004) found education to be a predictor of undertreatment; those lacking higher education reported more severe current and average

pain ratings than those that had received postsecondary education. Portenoy, Ugarte, Fuller, and Hass (2004) uncovered similar predictors when surveying pain reports among Whites, Hispanics and African Americans. In their study, African Americans and Hispanics reported greater pain. Interestingly income and education demonstrated the strongest association with disabling pain. Minority status was not a predictor of pain severity in this sample, but the minority participants tended to be of lower income and were less educated.

In a secondary analysis of 964 hospitalized adults, McNeill et al. (2004) explored correlations between several patient-level variables and pain intensity and interference (pain intensity's ability to interfere with usual activities). One specific research aim related to differences that may exist in pain management outcomes by age, ethnicity, gender, or educational level. Their analysis revealed factors that predicted poorer pain management including age over 65 years ($p = .04$), non-White ($p = .02$), and education of high school or less ($p = .025$). These findings are somewhat contrary to those reported by Deandrea et al. (2008), specifically with regard to age.

Other patient-centered factors contributing to undertreatment relate to past experience, meaning of pain, as well as individual, societal, and community-based norms around pain, and its ramifications (Fairchild, 2010). Well-known misconceptions continue to plague management of CRP including correctly operationalizing tolerance, dependence, and addiction, knowledge about dosing, scheduling of medications, titration, fear that pain discussions with providers will overshadow cancer treatment and not wanting to use pain medications too soon for fear of a ceiling effect (Cohen et al., 2008; McNeill et al., 2003). Negative beliefs about pain medications, often corrected through

education, have been associated with lower medication adherence (Kwon, 2014; Liang, Yates, Edwards, & Tsay, 2008). Conversely the same study found that belief in one's ability to successfully take medication (opioid self-efficacy) predicted pain relief (Liang, et al.).

Another patient-level factor impacting pain is psychological distress (Kwon, 2014). Higher scores on depression scales have demonstrated greater pain as well as anxiety, hostility, mood challenges and anger. Such emotional factors were correlated with poorer medication adherence as well (Kwon).

In a meta-analysis, Devine (2003) reviewed 25 psychoeducational studies published between 1978-2001. Although there was some difference found in effect on pain outcomes, serious methodological variations limit generalizability. Others have cautioned that educational endeavors, while helpful to enhancing self-efficacy, have a threshold and compete with other aspects described here such as meaning of pain, and cultural and societal influences (Oldenmenger, Smitt, van Dooren, Stoter, & van der Rijt, 2009; van der Peet et al., 2009). While differences can be found in pain management knowledge, effects on quality of life over time were not sustained through psychoeducational interventions. Devine takes the position that psychoeducational strategies range in efficacy, depend on multiple factors and should only be used as an adjuvant to analgesics.

These studies have highlighted the various factors associated with undertreatment that are primarily focused at the level of the patient. Several predictors are at the level of the individual such as age, income, education, ethnicity in some cases, and location of care. Reflections on some of the other reasons for undertreatment can be linked to

insufficient provider knowledge, specialty training, academic preparation or education and biases. The relationship between provider and patient level factors is largely absent from the discourse of undertreatment and remains largely unexamined. Rather, they have been held as parallel yet isolated entities.

Provider-level Factors

Unfortunately provider-driven deficiencies continue to play an important role in the undertreatment of CRP. Provider and system issues contribute to undertreatment and blend into the discussion of barriers or misconceptions around pain management already summarized in Chapter I. Now they will be discussed in relation to undertreatment.

Delivering quality care requires a competent and complete assessment. Without regular, timely assessment using valid and culturally appropriate tools, patients are at risk for undertreatment (Fairchild, 2010; McNeill, Sherwood, & Starck, 2004). Olenmenger and fellow researchers (2009) examined the factors hindering adequate pain management in 40 published studies addressing barriers. Reported most frequently by physicians and nurses were inadequate provider pain assessment and insufficient knowledge of management. Kwon's (2014) review had similar findings with physicians acknowledging first, that CRP is undermanaged and had largely remained unchanged overtime. In addition the most common provider-related factor reported was poor pain assessment, followed by a lack of knowledge, reluctance to prescribe and concerns with regulatory, legal and administrative constraints. Also cited were nurses' limited knowledge and reluctance to administer opioids (Kwon, Paice, & Von Reonn, 2014).

In concert with this self-assessment by providers, when hospitalized patients were interviewed in Sherwood and colleagues (2000) qualitative study, they cited lack of

provider education and competence in pain management as contributors to poor pain care. Reasons for poor care again are linked to misconceptions, lack of knowledge about pain medications, dosing and timely titration (Fairchild, 2010; McCaffery & Pasero, 1999; McNeill, Sherwood, & Starck, 2004).

Similar to attempting patient-directed educational interventions, researchers have directed attention to enhancing provider competence in pain care. Using outcomes such as changes in patient pain intensity, congruence between worst reported pain intensity and most potent medication taken (Patient Management Index) and knowledge and barriers to pain management researchers found little consistent influence by provider-aimed interventions in improvement in cancer pain management (Oldenmenger et al., 2009). Other studies have found a change in knowledge, however, there is no study demonstrating that improved awareness and understanding yielded improved pain outcomes (Huth, Gregg, & Lin, 2010; Kwon, 2014; Vallerand, Collins-Bohler, Templin, & Hasenau, 2004). There was some hope that emerged in a systematic review conducted by Cummings and colleagues (2011). While few, a handful of provider-directed knowledge focused interventional studies demonstrated some impact on patient pain intensity ratings. The authors describe several very specific components of successful programs, none of which targeted ethnic populations.

Overall findings in these recent critical appraisals are provocative in light of the directive posed by leading organizations that such multidisciplinary approaches will improve cancer pain care (APS, 2005; NCCN, 2014; WHO, 1986). Although these reviews discuss the challenges of interpretation based on methodological variability, attempts to validate international and national assumptions regarding quality pain care

have not been consistently substantiated. Speculation as to the causes of such negative findings include a lack of international consensus on end-point outcome measures, resulting in a multitude of dependent variables across studies thus making a collective interpretation difficult. Another critical factor is that many studies do not address multidisciplinary roles within the same intervention such that other disciplines' roles may have served as confounding variables, thus obscuring the intervention's main effect (Oldenmenger et al., 2009).

Thus far the discussion has summarized patient and provider-level factors that contribute to the undertreatment of CRP. Embedded within both of these sources of unsatisfactory pain care, are systems and regulatory factors. The following section briefly highlights some of these contributors.

Structural System Level Factors

Patients and providers interact within national, state and local systems of regulation. The national and state climate around pain care has vacillated over the years from concerns with undertreatment to overtreatment. Currently, there is a resurgence of concern with overprescribing of opioids, which was reviewed earlier in this chapter. The climate surrounding such concerns puts cancer patients' pain care at risk. Factors external to providers have been targeted as contributing to undertreatment that include economic, regulatory and insurance. Forces continue to stress that system-related impediments must be addressed and encourage quality improvement efforts (Gee, 2003; IOM, 2011; The Joint Commission, 2014).

Kwon (2014) summarized institutional level variables such as access to pain specialists as a barrier to CPR management. Services sought of specialists ranged from neuroablative procedures to psychosocial support to nonpharmacological pain resources.

Reimbursement for pain services is often inadequate and tied to procedural interventional care, a strategy reserved for a small component of cancer pain conditions (Gaskin & Richard, 2012; Kulich & Loeser, 2011; Paice & Ferrell, 2011). As part of reimbursement, there is less reward for providing cancer pain care and more on cancer treatment (Wong, 2013). Oncologists do not receive additional reimbursement for managing toxicities or symptoms; instead they are paid for giving expensive therapy. Seventy percent of revenue comes from cancer treatment products released in the last 10 years, and insurance regulations require payment for any and all FDA approved drugs regardless of outcomes (Newcomer, 2012). Newcomer suggests changing the current incentives for cancer care in a more balanced fashion, less weighted on expensive drugs and more on clinical quality of life and patient outcomes such as pain relief.

The Pain Standards provided by The Joint Commission (2014) require institutions and affiliated clinics to standardize their approach to providing an individualized comprehensive assessment, reassessment, management, and referral to specialists if the provider is not able to provide the service. In addition, they require institutions to provide pain education to nurses and physicians. The emphasis of these standards is on assessment and education and less on sustaining the effort of any improvements in pain care.

In summary, there are reimbursement-related incentives that deemphasize pain care, institutions are challenged to establish ongoing means to evaluate effects of

professional training and education, and ultimately have limited efforts toward evaluating patient pain outcomes. In addition, there are reluctance and limited resources for providers to refer to specialists for pain care, and this care is most often reimbursed for interventional procedures rather than a full-service pain management program.

Some of the most common barriers to adequate pain care have been summarized here, primarily addressing patient, provider and system level factors. A shared denominator for both professionals and patients has been limited or poor assessment, knowledge deficits, and widespread misconceptions about pain and its management. Barriers to effective pain care are prevalent, affecting the population with CRP. Large population-based studies have identified gender, stage of disease, site of care, educational level, and communication between providers as some of the major predictors of undertreatment (Deandrea et al., 2008; Fairchild, 2010; McNeill et al., 2004). Neither ethnicity nor culture has consistently surfaced in these reviews as explicit risk factors for inadequate care but possibly indirectly relate through other variables such as site of care, educational level, and communication barriers. The following section introduces Hispanic/Latinos in the United States and specifically in New Mexico, characterizes health outcomes in this population, and discusses cancer-related pain among this population.

Part II: Review of Hispanics and Health

Challenges of Defining Hispanics/Latinos in Health Research

Central to conducting research with any group is determining representation as a label or classification. The term *Hispano* actually emerged in the mid-1850s as Spanish and Mexican descendants staying in the United States after the Guadalupe-Hidalgo peace

treaty in 1848 became US citizens and intermarried with non-Hispanic Whites and American Indians. Periodic influxes of Mexican and Spanish immigrants to the US can be traced to waxing and waning historical labor needs, such as building railroads in the 1880s and farm labor needs in the 1940s (Marín & Marín, 1991). Hispanos are recognized as the ancestors of today's 5th- and 6th-generation Hispanics (Marín & Marín). In fact, the term is one of many used to describe people with Latin and Central American or Spanish national roots. In addition to Hispanic, other descriptors exist for persons of a similar ethnic group such as *Latino, La Raza, Spanish-speaking, Latin, Hispanoamericano*, and *Chicano* (Bathum & Baumann, 2007; Marín & Marín).

For the purpose of census reporting the Office of Management and Budget (OMB) defines Hispanic or Latino as "a person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin, regardless of race" (US Census Bureau, 2010, p. 2). The Intercultural Cancer Council (ICC), an advocacy organization housed at Baylor College of Medicine, dedicated to eliminating unequal cancer care in the United States through policy and research efforts, has similarly adopted the term Hispanic/Latino. ICC concurs that such a category subsumes a collective of cultures and origins that span the field of racial classifications and subgroups, acknowledging 'Hispanic/Latinos' as a "mosaic of cultures" (n.d.). The New Mexico Department of Health (2007) as well as the OMB uses categories of ethnicity for the purpose of identifying and trending disparities in health and access to care. There are two categories for reporting and categorizing ethnicity – Hispanic or Latino and Not Hispanic or Latino (US Census Bureau, 2010). "Hispanic" is the category used to capture those residents who see themselves of this heritage, nationality, lineage or country of birth of those

persons or ancestors before arriving in the US.

Finally, Marín and Marín (1991) suggest, for the purpose of clarity, that in health-related research the term Hispanic be used to signify persons residing in the United States that may have been born or find ethnic origins in Spanish-speaking Latin America countries or Spain. These authors make the crucial observation that labels are symbols of self-identity and a given designation over another may be preferred, still suggesting one way to operationalize Hispanic ethnicity is through self-identification. This approach bears a cautionary note: Not all people will respond positively and may prefer a different classification. Another limitation to ethnic labeling is that academia or health care institutions, or any other system of power may construct one meaning, which may not necessarily reflect the same meaning by those placing themselves in that grouping. Finally, there has been some evidence for generational diversity in labeling. Marín and Marín found the majority of first-generation respondents (87%) preferred the label 'Mexican' while the majority of the second-generation respondents (81%) chose "Mexican-American." These figures are somewhat dated, but it is important to consider the boundaries that such labeling creates as a choice of preferred self-identify, generational preferences, and whether the lens is the researcher's or a member of the given community. Conducting research with a population different from one's own calls for sensitivity to the limitations of language, terminology, and characterizations. Accepting these limitations and in an effort to maintain consistency with these various recommendations, I use the terminology Hispanic/Latino or Hispanic Latino throughout this paper when speaking of a cultural identity shared by participants in my research.

Hispanic Demographics in the United States

Hispanics are the fastest growing ethnic group in the United States and are affiliated with all of the US Census Bureau race categories (White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander). Hispanics completing the 2010 census reflected subgroups varying by cultures and origins. For example, 63% of US Hispanics are of Mexican origin, 9% are Puerto Rican, 3.5% are Cuban, and another 13.5% consider themselves of Central or South American heritage (US Census Bureau). Hispanics represent 16% of the total population of 308.7 million people in the US, increasing nearly 10% since the 2010 census data. These figures are predicted to continue increasing with the Hispanic populations growing four times faster than the general population such that by 2050 Hispanic/Latinos will account for nearly 30% of this nation's population (US Census Bureau, 2011).

New Mexico and Hispanics

Hispanic diversity is further illustrated in the state of New Mexico. In contrast to national figures of Hispanic/Latinos representing roughly 16% of the over 308 million people in this country, Hispanic New Mexicans account for 47.3% of the states' residents (US Census Bureau, 2014). Whites not of Hispanic origin in New Mexico represent only 39.4% of the population as compared to 63.6% nationally. Table 3 provides a summary of the various ethnic groups in New Mexico, accounting for the remaining percentage of residents.

The largest subgroup of New Mexico Hispanics selects Mexican ethnicity. However,there is a substantial number classified as "Other Hispanic or Latino" (17.0%). In New Mexico, this is thought to represent the long-term Hispanos who trace their

Table 3

Hispanic Population Comparison

Total Population	NM %	U.S. %
Hispanic or Latino (of any race)	46.3	17.1
Mexican	28.7	63.0
Puerto Rican	0.4	9.2
Cuban	0.2	3.5
Other Hispanic or Latino	17.0	24.3
Non-Hispanic or Latino	53.7	62.6
Black or African American Alone	2.5	13.2
American Indian and Alaska Native alone	10.4	1.2
Asian alone	1.6	5.3
Native Hawaiian and Other Pacific Islander Alone	0.2	0.2
Two or more races	2.4	2.4

Note. Adapted from U.S. Census Bureau, 2011

ancestry to Spain rather than Mexico. The ethnic diversity among New Mexicans claiming Hispanic or Latino descent is a potentially significant factor when making assumptions about cultural beliefs and practices in research efforts.

In addition to ethnic influences, geographic and economic factors play a role in experience and health outcomes. New Mexico is uniquely situated in this regard, being only the 45th most densely populated state in the United States. Although the state has a large landmass, it has one of the lowest per capita densities with approximately 17 persons per square mile. A point of comparison is the United States land mass with an overall density of 87 people/mile (US Census, 2010).

New Mexico is a rural state with just over two million residents. Living in and around Albuquerque are approximately 662,564 of its residents, making it the state's largest urban center. Significant issues of access to health providers and specialists exist

for the remaining 70% of the state living in more distant communities. There are only seven cities in the state that have a population greater than 30,000. Although nearly 40% of the Hispanic population lives in the urban area of Albuquerque, statewide there are proportionally greater numbers in the northern regions than Whites. Population distribution is an important issue when addressing the burden of disease, specifically cancer in New Mexico. Incidence rates may be higher for the more populated counties but the burden imposed will vary by locality and access to care (New Mexico Department of Health, 2007).

Economic variables also impact health-related outcomes. New Mexico is one of the country's poorest states with 19.5% living at or below the poverty level (14.9% nationally). In New Mexico, 25% of working age Hispanics are at or below the poverty level, with those younger than 17 representing even higher poverty rates (37%). Hispanics in New Mexico make an average income 70% of their non-Hispanic counterparts.

Nationwide, 34% of Hispanics lack health insurance compared to 10% of Whites and 20% of African Americans. Twenty-five percent of New Mexicans do not have health insurance, compared to 11% of non-Hispanic Whites and higher uninsured rates among the younger residents – those18-24 years of age (Pew Research, 2014).

Age is especially relevant in New Mexico where approximately 50% of Hispanics are below the age of 25 in contrast to Whites with over 70% above this age (Pew Research, 2014; US Census Bureau, 2011).

With these variables of more challenged health care access, lower socioeconomic position, and a large number of uninsured residents, the potential for inferior health

outcomes exist for New Mexico Hispanics.

Situating Health Care Research with Hispanics in the Context of Cultural Norms

Collapsing a group of individuals with widely ranging stories of identity and history into a stereotypical collective is not an uncommon occurrence in health science research. Nonetheless, some broadly shared cultural values have been described in the literature. I will discuss some of these principles in terms of how they may or may not inform research endeavors and clinical practice.

Culture is a central factor when examining screening behaviors, reactions to disease, and approaches to seeking care (Clark & Redman, 2007; Freeman, 2004; Lorig, Ritter, & González, 2003). Cultural norms interface with a variety of health-related issues (Hawley, Chavez, & St. Romain, 2007; Juarez, Ferrell, & Borneman, 1999; Marín & Marín, 1991; Mayo, Sherrill, Sundareswaran, & Crew, 2007; Mulvaney-Day, Alegria, & Sribnery, 2007; Ruiz, 2007; Sammarco & Konecny, 2008). Among Hispanic communities, social support consistently correlates with health, adaptation, and accomplishment (Duggleby, 2003; Gresenz, Rogowski, & Escarce, 2009; Mulvaney-Day, Alegria, & Sribney; Negy & Woods, 1992; Ruiz). The concept of familismo is a central support resource. Familismo reflects a welcome commitment (rather than burden) of caring for family over one's self. The extended family takes precedence over the individual, enhancing family solidarity (Duggleby; Vilarruel, 1995). Marín and Marín (1991) refer to this concept in much the same way as "familismo": A strong identification with one's family, grounded in loyalty, cohesion, and mutual responsibility for each

other. The sharing of burdens serves to protect or minimize life stressors. The foundation of this commitment appears to be grounded in three principles:

•Sense of obligation to provide support (emotional or material)

•Trust in family for support

•Family as modeling behavioral and attitudinal position or point of reference

Once traditionally defined as biological family relations, *familismo* has broadened to include friends and neighbors (*comadres* and *compadres*) due to a geographical barrier and difficult access to more immediate family members (Marín & Marín, 1991; Ruiz, 2007). These individuals hold the same expectations and benefits as blood relatives. Although members of this support network have broadened over time, the value itself has transcended generations and number of years in the United States to varying degrees (Marín & Marín, Negy & Woods, 1992). Researchers must consider and respect the notion of *familismo* and how its emphasis among Hispanics may impact a particular topic or behavior related to health or illness. The current study does not aim to directly gather data from family members' but remembering that family and support are influential factors in the experience and decision-making for Hispanic persons living with CRP (Juarez, 1996; Juarez et al., 1998; Villarruel, 1995; Villarruel & Ortiz de Montellano, 1992).

Confianza, (trust in another), and *personalismo*, (personalized, individualized, and respectful caring) are other cultural norms that are often severely lacking as Hispanics encounter the health care system and providers (Clark & Redman, 2007; Duggleby, 2003; Larkey, Hecht, Miller, & Alatorre, 2001; Villarruel, 1995). *Fatalismo*, the assumption that a condition or symptom is inevitable, or naturally associated with an underlying

condition such as cancer, or the necessary burden of such suffering as part of a religious penalty, is yet another cultural perspective that may influence outcomes (Larkey et al., 2001). Western medicine is not perceived as trustworthy or personalized and is often only consulted after self, family, friends, or traditional healers. Marín and Marín (1991) further characterize common aspects of Hispanic culture, summarized in Table 4.

Cultural competence, which requires cultural humility, or a willingness to look at the role of self – beliefs, values, past experience and assumptions about others, is critical when engaging with persons of varying backgrounds and histories (AACN, 2010).

Cultural competence is said to be operationalized when "respect for the inherent dignity of every human being, whatever their age, gender, religion, socioeconomic class, sexual orientation, and ethnic or cultural group is being demonstrated; when rights of individuals to choose their care provider, participate in care, and refuse care, are respected" (California Endowment, 2003, p. 102). Cultural competence implies that the

Table 4

Common Features of Hispanic Cultures

Characteristic	Description
1. Allocentrism	Collective approach to objectives, attitudes and decision-making; interdependent, influenced by group rather than individual/self; trust and confidence in the group.
2. Simpatía	Notion of cooperative, friendly encounters; engaging respectfully and in harmony in relation with others.
3. Respecto	Positionality – power or influence of others, relative to self; deference to those perceived as powerful by profession or economics. Valuing support to authority or those in charge.
4. Personal Space	Preference for closer sharing of space; less distance during personal encounters.
5. Time Orientation	More present-focused in terms of planning, punctuality and efficiency; flexible position on time

Note: Adapted from Marín & Marín (1991)

researcher or provider acknowledges their own personal biases, remains open and aware of individual variations, not making assumptions or generalizations based on stereotypes or their own biases.

Having said that, the characteristics summarized here do appear to be important cultural threads shared among many Hispanics, yet these constructs are not necessarily adopted by all. Without typecasting but instead remaining aware and respectful of the potential impact these play on the research process is cause for thoughtful construction of the design, interview encounters, and analysis processes.

Hispanic Health Outcomes and Disparities

Hispanics are the fastest growing minority group in the US and as a population they are burdened by disparities in health care and outcomes when compared to non-Hispanics (Cook, McGuire, & Zuvekas, 2008; Mitrani, 2009). Hispanics continue to experience wider gaps in insurance, have higher levels of underinsurance, and access to care is limited often by language and cultural issues (Cook et al.). The Institute of Medicine (IOM) defined disparities in healthcare as "racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions" (IOM, 2003, p. 32).

Some evidence suggests improvements in health outcomes, such as reduced rates of cholesterol control among ethnic minorities. However for many other chronic diseases, public health issues and prevention and early detection efforts, Hispanics continue to lag in attaining improved outcomes (Agency for Healthcare Research and Quality, 2008; IOM, 2003). Examples of chronic diseases with disparate outcomes include diabetes, eye

diseases and vision impairments, and liver, stomach, and cervical cancers (Mitrani, 2009; National Center of Minority Health and Health Disparities, 2010). Serious public health conditions linked more to lifestyle include obesity, HIV/AIDS, sexually transmitted diseases, substance abuse, family and intimate partner violence, as well as an array of mental health issues that may correlate with any of the above conditions (Mitrani). The facts remain that minority groups, inclusive of Hispanics, are less likely than Whites to have health insurance, have fewer choices in care, are less likely to have a primary provider, and are more likely to receive care in emergency rooms (Dayer-Berenson, 2011). Freeman (2004) reminds researchers and healthcare providers that cancer inequities occur from a complex set of factors that are socially, economically, and culturally rooted within systems of government, community, family and health care delivery.

As previously discussed, culturally shared knowledge and behavioral norms are important variables in health care and individual care-seeking behavior (Larkey, Hecht, Miller, & Alatorre, 2001; Negy & Woods, 1992). Gresenz and colleagues (2009) expanded the lens to include issues that may be intimately connected to access such as community dwelling, economic, institutional structures, and public policy. Their retrospective design considered not only predisposing factors such as nativity and acculturation, but also enabling factors such as insurance coverage and language. They examined contextual variables including the structure and capacity of the health care "safety net" (p. 1544). Interestingly, they found that social networks created in Hispanic communities served as a buffer to barriers, and, in fact, those living in areas more highly populated with other Hispanic immigrants or Spanish speakers had greater access to care.

Gresenz et al. suggest that providers and policy makers address the needs of Hispanics who have less access to such support networks within the community. Their findings do not negate previous reports but actually add to the complexity of disparity, access, and health outcomes. Findings reported in *Unequal Treatment* (IOM, 2003) identified the multiple layers and sources of factors contributing to health disparities. In addition to those already reported here, they include such issues as provider stereotyping and biases, time constraints of clinical encounters, cognitive and language barriers, and cost pressures.

Parallel to Cook and colleagues' (2008) reference to the significance of language, Mulvaney-Day and colleagues (2007) describe its importance in forming social links, with both mental and physical health being deeply connected to family support. Use of language is social and not static or neutral, changing as is best suited for a given condition or audience (Allen & Cloyes, 2005). Census data in New Mexico reflect 28.7% of the 8.2% claiming to be foreign born do speak Spanish at home. However, only 9.4% speak "less than very well" (US Census Bureau, 2000). Language is yet another factor that impacts access and ultimately, health outcomes (Gresenz, Rogowski, & Escarce, 2009; IOM, 2003).

The Agency for Healthcare Research and Quality (AHRQ) has targeted specific groups for health care research. These include racial/ethnic minorities, persons of low income; women, children, older adults, persons with disabilities, and individuals living in rural communities (2008). New Mexican Hispanics can simultaneously be members of multiple groups - living rurally, of low income, a member of an ethnic minority, disabled, and any of the gender/age categories. It is important to contextualize these variables in

the realm of cancer among New Mexican Hispanics.

New Mexico accounts for 10,210 of the 1,665,540 new cases of cancer estimates for 2014 (ACS, 2014). Data from the New Mexico Tumor Registry (NMTR) report that although cancer incidence and mortality have been declining for New Mexican Hispanics, in 2007 Hispanics still accounted for 23% of new cases and 33% of the mortality rates (2014). Nationally, Latinos have lower incidence rates for the most common cancers; however, there are disparities among specific cancer sites, a fact for New Mexico Hispanics as well. Table 5 compares incidence and death rates between the leading cancers nationally, the Hispanic subgroup nationally, and New Mexican Hispanics.

Similar to national figures, the top cancer sites among Hispanics are prostate, female breast, colorectal, and lung. According to Cancer Facts and Figures for Hispanics/Latinos 2012-2014, prostate, breast, colon/rectum, and lung cancers accounted for over half of all the new cancers among Hispanics nationally (ACS, 2012). The same is true in New Mexico. However, rates are lower for most of the most common cancers when compared to all national and all Hispanic cases. There is an exception in New Mexico with breast and prostate cancers. Relative to all new cancer cases diagnosed for each, the rates for both breast (33%) and prostate cancer (30%) represent a significantly greater proportion of the total new cases (NM Tumor Registry, 2014). While incidence rates are similar for all national Hispanics for lung and colon cancer, a slightly higher percentage will die of both of these among New Mexicans.

Incidence and death rates for cervical cancer are higher among Hispanic women nationally and in New Mexico. (ACS, 2012; NM Tumor Registry, 2014). A cancer

Table 5

Leading Cancer Site Comparison of Incidence and Mortality

Cancer Site	**National Figures** ***All Cases (%)*** * 2014 New Case	Deaths	**National Figures** ***Hispanic Only (%)*** ** 2012 New Cases	Deaths	**New Mexico Figures** ***Hispanic Only (%)*** 2007 *** New Cases	Deaths
All Sites	1,665,540	585,720	112,800	33,200	2388‡	954‡
Prostate	233,000 (27%)	29,480 (10%)	15,400 (29%)	1,600 (9%)	354 (30%)	59 (6%)
Breast	232,670 (29)	40,000 (15)	17,100 (28)	2,400 (15)	397 (33)	72 (16)
Lung & Bronchus	224,210 (14)	159,260 (27)	8,900 (8)	5,300 (16)	204 (8)	171 (17)
Colon & Rectum	136,830 (8)	50,310 (9)	10,700 (10)	3,500 (11)	265 (11)	120 (13)
Liver & Intrahepatic Bile Duct	24,600 (3)	23,000 (4)	3,100 (6)	2,700 (8)	77 (3)	66 (7)
Leukemia	52,380 (4)	24,090 (5)	4,100 (4)	1,600 (5)	59 (3)	24 (3)
Stomach	<2%	<2%	1,700 (3)	1,600 (5)	19 (3)	28 (6)
Cervix	<2%	<2%	2,100 (4)	<2%	25 (2)	12 (3)

Table adapted from the following sources:
* percentage of all New Cases/Deaths nationally (ACS, 2014)
** percentage of Hispanic New Cases/Deaths estimates for 2012 (ACS, 2012)
*** Incidence of new cancer and mortality – *Hispanic only* average number of new cases and percentage of each cancer reported in NM for the same time period (2006-2010) (NM Tumor Registry, 2014)
‡ 2014 Estimates (ACS, 2014)

disparity exists for both stomach and liver cancer, with rates higher among Hispanics nationally and in New Mexico, than non-Hispanics, (ACS; NM Tumor Registry).

Caution is recommended when generalizing about the data presented here as changes in trends and comparisons may reflect chance variation when comparing incidence and mortality (New Mexico Cancer Facts & Figures, 2007). Collectively divergence in cancer site, incidence and mortality by ethnicity may reflect unique concerns, barriers, and challenges for Hispanics receiving cancer care and management of cancer-related symptoms, including pain for Hispanics. Hispanics account for 27% of all new cases in the state and 32% of the cancer-related deaths.

Many of the findings discussed here reflect research that has occurred in the many years since Congress recognized that lower quality healthcare exists for ethnic minorities, even when insurance and income variables are controlled. The IOM committees' charge in 1999 and the resulting published recommendations have continued to direct and reinforce much of the ongoing research in the area of health disparities (HHS, 2011; IOM, 2011).

Quantifying disparities and measuring the interplay of these complex and multilayered issues of health access, care, and outcomes by ethnicity is beyond the scope of this study. It is however, important to illuminate such aspects external to the individual experience, as they inform this exploration of CRP among Hispanics.

The previous sections addressed contemporary knowledge related to treatment of cancer-related pain and its undertreatment while defining and portraying Hispanics and health care issues in the United States and New Mexico. Factors such as bias, assumption, culture, language, position, and power, which add layers to an already inadequately addressed common health issue for those with cancer, have yet to be discussed. The following section drills down another level, examining how cancer pain undertreatment intersects with minority populations, particularly Hispanic/Latinos and considers the implications for practice and research.

Part III: Review of Cancer-Related Pain Among Hispanics

Describing Undertreatment

Although ethnicity did not stand out as a specific risk factor or predictor of undertreatment in recent systematic reviews (Deandrea et al., 2008; McNeill et al., 2004), there is a body of research that has isolated an unequal burden of pain by ethnicity

(Cleeland et al., 1997; Green et al., 2003; Hernandez & Sachs-Ericsson, 2006; Stephenson, Dalton, Carlson, Youngblood, & Bailey, 2009). Recognizing the limitations of these reviews posed by methodological incongruity, a discussion of the body of research illuminating disparities by ethnicity are brought to light here.

In a classic study conducted through the Eastern Cooperative Oncology Group, Cleeland and colleagues (1997) described prescribing patterns and severity of CRP in minority outpatients. They found 65% of 281 minority participants did not receive guideline recommended analgesic prescriptions compared to a nonminority group ($p <$ .001). Among their sample, Hispanics reported less pain relief than other minority groups and greater fear of medication side effects.

Other studies demonstrated greater pain reporting as well as higher distress from pain in Hispanic populations (Anderson et al., 2002; Cleeland, 1994; Im, Guevara, & Chee, 2007; Ng et al., 1996; Todd et al., 1993). Hernandez and Sachs-Ericsson (2006) found that chronic pain was reported at a higher rate among Hispanics compared to Caucasians, and this difference was magnified in the presence of depression.

Also, not exclusively related to cancer pain, Green and coworkers (2003) exposed ethnically rooted disparities that cut across types of pain, reminding providers, researchers, and health policy activists as well as the public that differences in care are not isolated to a particular type of pain. Inadequate and substandard pain care exists with a range of clinical conditions among ethnic minority groups.

A study by Juarez and colleagues (1999) found poorer quality of life outcomes and greater pain reports for Hispanics when compared to Caucasian and African Americans all experiencing CRP. For example, when compared to Caucasian and

African Americans, Hispanics reported greater difficulty coping ($p < 0.02$); experienced more depression ($p < 0.01$); and greater family distress ($p < 0.001$). They also reported higher "worst pain" ratings ($p < 0.03$); "pain distress" ($p < 0.01$); "family distress" ($p < 0.001$); and worse outcomes for impact on "personal relationships" ($p > .001$). Interestingly, in spite of such reporting, Hispanics in the sample scored significantly higher for mood ($p < 0.001$) and general happiness ($p < 0.02$). Cleeland and colleagues (1994) reported similar findings.

When people of color were compared to Caucasians, Rabow and Dibble (2005) found minority patients at the end of life suffered a greater burden of pain. Of 99 patients receiving palliative care in their longitudinal study, minorities, including Hispanics, consistently reported greater pain on average ($p = .05$) and current pain ($p = .03$). In addition, they consistently had lower opioid-based analgesic use.

Two studies found the actual treatment setting to be an additional barrier. Both studies reported inadequate analgesic prescribing for Hispanics and African Americans receiving care at a center that predominately treated ethnic minorities when compared to similar groups receiving care in a nonminority center (Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997; Cleeland, Gonin, Hatfield, Edmonson, Blum et al., 1994).

A qualitative study by Im et al. (2007) using a feminist theoretical foundation described four major themes among Hispanic patients experiencing cancer-related pain as related to inadequate pain management. These were 1) lack of communication about being undertreated; 2) enduring of pain was tied to traditional gender roles which guided behavior; 3) personal needs were set aside on behalf of the greater needs of family over self; and 4) confliction in the experience, while interfacing with an unfair healthcare

system they simultaneously were appreciative of any treatment received.

Similar findings were reported in a study using structured interviews with 31 socioeconomically disadvantaged African Americans and Hispanics. In addition to reporting difficulties related to communication, there was a reluctance to report pain, a belief in the value of stoicism and concerns related to addiction and tolerance (Anderson et al., 2002).

Many of these studies point to the role of cultural beliefs and behaviors that may influence such differences in pain and its management. The following section reviews some of the literature addressing the important role of culture as it specifically applies to Hispanics and pain perception and experience.

Culture, Meaning and Experience

> *"Yet only through communication can human life hold meaning."*
> *Paulo Freire, 1970, p. 63*

The gaps demonstrated here in pain care by ethnicity must be considered within the context of culture. As a reminder, culture is defined as an anthropological and social concept held by a particular group where values, beliefs, norms, patterns of behavior and ways of knowing are shared, learned and passed on. These cultural norms guide decision-making and actions in addressing human experiences (Bent, 2003; Leininger, 1985).

Davidhizar and Giger (2004) as well as others found culture to be a strong influence on the experience, expression, and outcomes of cancer-related pain in Hispanics (Duggleby, 2003; Im et al. 2007; Im, Guevara, & Chee, 2007; Juarez, Ferrell, & Borneman, 1998; Juarez, Ferrell, & Borneman, 1999; Kandula, Lauderdale, & Baker,

2007). Understanding unique cultural norms is critical in cross-cultural research (Campbell et al., 2009; Im, Ho, Brown, & Chee, 2009). Several factors that can frame cultural influences as they may influence care have been described, including communication, space, social organization, time, environmental control, and biological variation (Giger & Davidhizar, 2004). Some of these considerations have been reviewed above as they may affect general health care outcomes. The notion of cultural normative influences can be further explored within the complex construct of pain and specifically CRP.

Communities socialize individuals in their culture as to what is expected of them in given situations, what their roles are, and how to act/behave (Callister, 2003; Dayer-Berenson, 2011; Juarez, 1996). Pain can also be assigned a particular meaning or purpose, based on tradition or custom (Callister; Villarruel, & Ortiz de Montellano, 1992). Health care providers must assess and intervene with an awareness of the context, meaning, and cultural influence pain may have for the individual.

Cancer-related pain brings along with it a central concern – the meaning and symbol of that pain. We assign meaning to most things in our lives. The experience of pain, when considered through the lens of what that pain means, certainly has the potential for emotional responses (Campbell et al., 2009).

In an ethnographic study with Mexican-Americans experiencing a variety of pain types, Villarruel (1995) identified four themes related to pain meaning, its expression, and care of self and others. These themes are summarized as 1) pain as an all encompassing suffering; 2) the accepted obligation to bear pain; 3) to endure pain stoically, privately; and 4) the paramount virtue and centrality of caring for others. Pain

among these Mexican-American informants was not only physical, but also personal, interpersonal, social and spiritual.

Personal aspects included physical and emotional manifestations such as loss of function, mobility, spirit or energy. The *interpersonal* domain included loss of or diminishing relations with loved ones as well as separation from these central relationships because of pain. Loss of cultural pride and dignity were important aspects of the *social* theme found among these informants. Finally, in the realm of *spiritual*, aspects, conflict and disharmony between God and the individual were described.

These emerging themes resonated with her earlier ethno-historical research exploring culture and pain from a Mesoamerican view (Villarruel & Ortiz de Montellano, 1992). Stoicism, for example, was exalted; pain and suffering were considered human fate and a consequence of immoral behavior; and to endure pain was valued and admired. Understanding to what extent these epistemic forces remain in contemporary generations is the work of researchers and providers working with people of this ancestry.

Campbell and colleagues (2009) addressed meaning of pain among Latinos and found *'destino' /destiny,* luck or chance as a reason for pain in one's life. Embedded in this perspective is a level of acceptance that may be mingled with fatalism although, as the authors admit, this has not been extensively researched in this population. Further compounding understanding is the nature of the pain as being affiliated with an underlying cancer and whatever other meanings may or may not be included.

Juarez (1996) has summarized similar constructs and brought others to light. For example she notes the hot-cold system that is found among Mexican-Americans, Puerto Ricans and other Latinos, believed to contribute to illness or pain. Although it is not a

direct reflection on meaning, perceiving pain as hot or cold may influence receptivity to particular biomedical treatments or folk remedies.

Nurse researchers and others have developed models for understanding the many domains of the pain experience. Presented in Chapter 1, Padilla and colleagues, for example, developed a framework for identifying and categorizing the many aspects to a pain experience (Padilla, Ferrell, Grant, & Rhiner, 1990). This model calls for the inclusion of understanding the pain from a cognitive perspective; what is it that the person thinks this pain means or represents?

Bates suggested another model for understanding pain – a biocultural model (Bates, 1987; 1988). This model acknowledges and accounts for how expectations, attitudes, meaning, and emotional responses are constructed through observations within a cultural group. These influences are primarily developed through the immediate circle of one's community and family members (Figure 3). Bates' model suggests that physiologic, psychological/behavior responses, and sociocultural factors influence a pain experience and aid interpreting a relationship between pain and culture. It is important to note that a difference in neurophysiological systems by members of different ethnic groups is not assumed. Instead, the author assumes humans have similar biological reactions to pain. The sociocultural and environmental features are felt to hold a more varying and dynamic place in the model. It is important to note that economic or structural factors, centrally linked to the experience of pain, are not part of this model.

Experimental Endeavors Targeting Disparate Cancer-related Pain Care

Larkey and colleagues (2001) stress the importance of designing 'interventions that fit the worldview of the targeted group and parallel *their definitions* of benefit, harm,

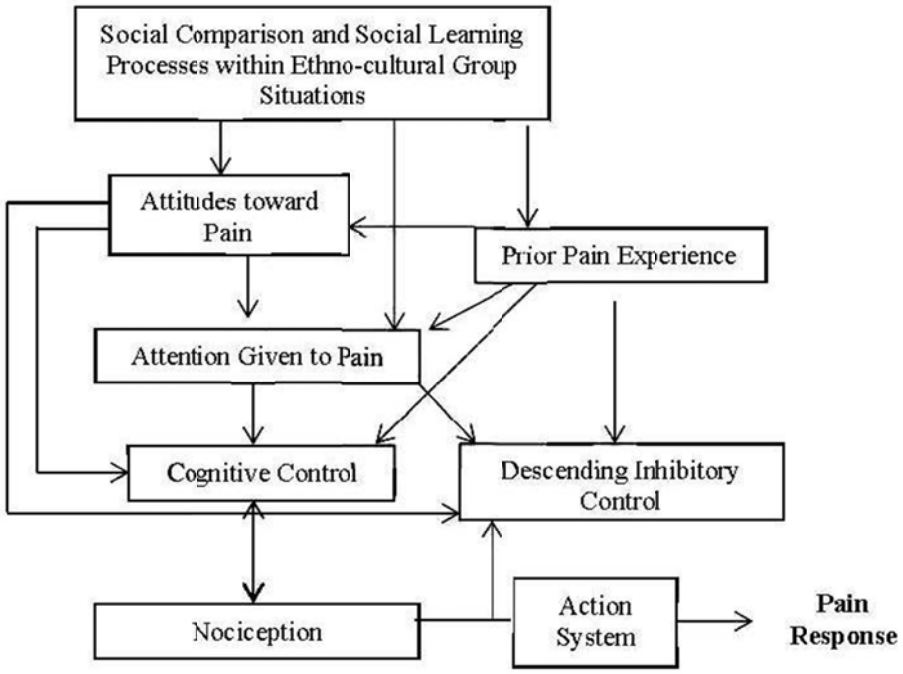


Figure 3. Biocultural Model of Pain Perception (Bates, 1988)

resources and power" (p. 66). Interestingly, very few studies incorporated emic definitions in their intervention and have been grounded on little qualitative data. I will begin by summarizing related interventional research. Literature looking at meaning of pain and cancer pain specifically has been addressed throughout this chapter and the fewspecific studies conducted with Hispanics/Latinos experiencing CRP will close this review.

Kalauoukalni, Franks, Oliver, Meyers, and Kravitz (2007) focused on communication when using a psychoeducational intervention to decrease patient-clinician miscommunication among persons experiencing CRP. This secondary analysis of a randomized control trial included minorities. Individualized education and practice using scripted physician-patient discourse about their personal pain control issues was hypothesized to increase knowledge of pain self-management, misconceptions, and

perception of control over pain. Consistent with the literature, the minorities had significantly greater pain at baseline (p = .05). Differences in pain intensity ratings were eliminated in the experimental group but unchanged in the control group.

When appropriate and agreed upon by the participants, role-playing could be incorporated as one form of education with the intent of impacting a more collaborative encounter with healthcare providers. Kalauokalani and colleagues (2007) suggest that role-playing as a form of coaching and empowering communication may serve as a catalyst for more engaging provider involvement and responsiveness. The constructs of collaboration, communication, and empowerment all address some of the complexity and gaps in pain care that have been identified (Bates et al., 1993; Im et al. 2007; Im, Guevara, & Chee, 2007; Kandula, Lauderdale, & Baker, 2007; Larkey et al., 2001; Villarruel & Ortiz de Montellano, 1992).

Partially reviewed earlier, Juarez and colleagues (1999) used a similar educational intervention with cancer patients receiving pain and symptom care in homecare or hospice agencies. Conducting a standardized educational program these researchers evaluated outcome variables measuring quality of life, knowledge and beliefs and pain measures before and after the teaching session in a sample of Hispanics, African-Americans and Whites. Not explicitly addressed in the report were ways the researchers tailored the teaching to be culturally relevant and sensitive, although the authors did discuss the imperative for such directions. The analysis from this interventional study examined only between group differences (summarized above) and did not look at in-group change.

More recently, Devine (2003) conducted a meta-analysis of the effect of

psychoeducational interventions in adults with CRP. Unfortunately this review did not report ethnicity data and the methodology and reporting variation among the 25 studies selected must temper interpretation. The major findings from this study supported the use of relaxation-based cognitive behavioral interventions, education on analgesic use and supportive counseling to reduce CRP. These interventions may be conducive to a culturally tailored approach to meet the needs of diverse ethnic groups.

Davidhizar and Giger (2004) similarly examined the most prominent and evidence-based culturally sensitive strategies for assessing CRP. Although pain is a universal experience, care must be tailored to the individual. Relevant key approaches are outlined here:

1. Culturally appropriate assessment tools.
2. Incorporate understanding of variations in affective responses (influenced by culture) into care.
3. Recognizing and respecting the role of language and misunderstanding, miscommunication and meaning that influences transmission of knowledge and experience.
4. Expression or acknowledgement of pain may not be culturally appropriate and tailoring care as needed.
5. Engage in personal reflection, identifying one's own values, beliefs, and possible biases that influence delivery of equitable and sensitive pain care.

The literature has demonstrated that purely informational /educational approaches are limited in their usefulness in that they fail to incorporate individual beliefs and tend to be "decontextualized" (Mishra et al., 1998, p. 655). The examples provided here have

enlisted predictors of undertreatment such as miscommunication/language, knowledge deficits, and assessment strategies to address CRP disparities in Hispanics. These interventions have been largely based on the reported evidence and statistical configuring that attempt to unravel and describe undertreatment rather than from the voices of Hispanics experiencing pain.

Qualitative Literature on Hispanic Latinos and Cancer Pain

Two studies are reviewed here that direct their inquiry to those with such pain. In 1998 Juarez and colleagues used Bates Biocultural model (1985) and the Impact of Pain on the Dimensions of Quality of Life model (Padilla, Ferrell, Grant, & Rhiner, 1990), both reviewed earlier in this text, to frame their qualitative study. Open-ended questions followed responses to the Hispanic Pain Experience Questionnaire to elicit influences of culture on cancer pain management in Hispanics. Eight themes emerged related to culture, some with similar tenor to earlier findings:

- Stoicism: Taught not to complain
- Family Medicine Woman
- Follow and Believe in God
- Folk Healers
- Beliefs about Medications
- Family of Central Importance
- Advice from Family/Neighbors
- Advice from Pharmacist

This study also captured unique aspects such as withdrawing in order to conceal the pain from loved ones. Pain descriptors were more emotive among this sample of

Hispanics with CRP, reinforcing the recommendation to acknowledge and integrate the variation of affective responses into pain care (Davidhizar & Giger, 2004). Managing pain reflected common strategies as well as folk remedies. Preparations such as traditional herbs and teas (*cancerina* with cat claw, *arnica, cola de caballo*/horse tail, lemon and orange leaves), assumption that injections of vitamins would benefit during illness, use of ointments (*crema de abeja*/bee cream), and combinations using rattle snake specifically to treat the underlying cancer, were also perceived as therapeutic. Although a structured tool guided the interviews, themes surfaced that provide a beginning understanding of some of the cultural variables surrounding a pain experience.

Cohen and colleagues (2004) conducted a challenging study using a hermeneutic phenomenological design with open-ended questions designed to bring forth descriptions of symptoms participants were having related to cancer. This study was not exclusively designed for Hispanics but 2 of the 10 informants were Hispanic. The most provoking finding was the reminder that pain may be disguised as other symptoms. A willingness to openly discuss other symptoms may exist but pain, often linked to meaning of the underlying disease, is not always as easy for the individual to disclose or confront. Pain assessment must go beyond the use of objective measurable scales such as 0 to 10 ratings, expanding in ways that recognize the potential for underreporting, especially when pain is linked to death awareness.

Summary and Rationale for Study

Green et al. (2003) acknowledge the significant lack of knowledge and gap in the literature regarding the pain experience and treatment for ethnic minorities. They suggest future direction for research should include understanding patient level influences such as

cultural beliefs and decision-making influences. Villarruel and Ortiz de Montellano (1992) recognized many years ago the need to develop a clearer understanding of pain behaviors among Mexican-Americans in order for nurses to provide culturally competent, sensitive and specific pain care to this population. Unfortunately, from that time forward, the literature has scant evidence of exploring the CRP experience in Hispanics through qualitative means. As can be seen in this chapter, the majority of these scientific endeavors focused first on capturing the disparities, and secondly attempting to isolate risk factors for undertreatment through descriptive analysis. Some of the studies used experimental designs to modify differences in care however little literature exists from a qualitative perspective to first hear the voice of experience of CRP, including Hispanics. Although some of the groundwork has been laid in describing the meaning of pain in populations classified as Hispanic/Latino or Mexican-American (Cohen et al., 2004; Juarez et al., 1998; Villarruel & Ortiz de Montellano), none of these works have included a perspective on external factors that influence CRP order to characterize personal identity and meaning, provider, and healthcare system level factors from the perspective of those living with cancer-related pain. Further exploration of how Hispanic Latinos describe their experience of CRP will strengthen current knowledge and care for this population.

Using an educational frame, Freire (1970) suggests a deep reciprocity must exist between teacher and student. He favors a more dialectical approach that honors and incorporates shared decision-making, inclusive of individual and social dimensions of a phenomenon as a means toward empowerment and change. Such a model has not been

used to understand and modify the experience of CRP and only in a limited fashion in cancer health promotion research (Mishra et al., 1998).

Freire (1970) refers to 'object' as the listener or the patient. The 'subject' is narrating (teaching) to the object. "The teacher talks about reality as if it were motionless, static, compartmentalized, and predictable. Words are emptied of their concreteness and become a hollow, alienated and alienating verbosity" (Freire, p. 57). Should this same hermeneutic be applied to many of the research approaches in relation to CRP: *negotiating* experience rather than *knowing* it? The first steps are to create an opportunity to describe CRP from the perspective of Hispanic Latinos as subjects, rather than objects. Greater understanding of a culturally embedded experience and meaning may then raise consciousness and improve care.

I have summarized the evidence on treatment for CRP, explored prevalence, and described possible reasons for its undertreatment, including patient, provider and system-level factors. A description of the general population has been provided, tailored to capture the specific characteristics and issues of Hispanics in New Mexico where data collection occurred. Finally I have summarized how cancer pain treatment and undertreatment have been analyzed in this population, mostly rooted in objectivist epistemology, with very few studies examining this concept from a qualitative descriptive perspective (Crotty, 1998; Sandelowski, 2000; 2002).

Culturally tailored interventions need to be developed that are built from both qualitative *and* quantitative studies, addressing the unique values, beliefs, histories and behaviors of Hispanics (Mitrani, 2009, p. 3). The following chapter presents the research

methods, outlines the design and data collection process, and describes the methods used for data analysis and for interpretation of the findings.

CHAPTER III

METHODS

After reiterating the study purpose and aims, this chapter outlines the rationale for the chosen research design, population and sampling methods, data gathering methods, analysis, synthesis, and ethical considerations.

To review, the purpose of this descriptive qualitative study was to explore how Hispanics/Latinos living in New Mexico experience CRP in their daily lives and how these experiences are influenced by culture, local social/environmental, and healthcare structural and provider-level factors.

Specific Aims and Research Questions

Aim 1

Explore dimensions of the CRP experience as described by Hispanics/Latino participants.

RQ1: *What characterizes the experience of CRP among New Mexican Hispanics/Latinos?*

Aim 2

Describe participants' perspectives of how local, institutional, and provider-level factors influence the experience of CRP among Hispanics/Latinos.

RQ2: *What external factors influence the experience of living with CRP among New Mexican Hispanics/Latinos?*

Epistemology and Research Design

Using research methods that are grounded in a constructionist epistemology allows discovery of new knowledge to emerge when little is known about a particular phenomenon (Morse, Swanson, & Kuzel, 2001). Such an approach creates opportunity for an expanded exploration of facets of a given phenomenon, such as CRP. As summarized in Chapter II, there is substantial evidence reporting the clear discrepancies in pain management received by various minority groups, described largely using empiric measures. Missing from the literature are studies offering emic insight into the actual experience of CRP for those having this type of pain or how these experiences might be partially shaped by cultural, local, and systems factors. Qualitative inquiry can expand our understanding of reported empirical data, adding a powerful richness to the scientific body of knowledge sufficient to change or modify perceptions and positions, influence practice, and ultimately improve care (Morse et al.).

Qualitative Descriptive Inquiry

The study at first glance may seem most suited for an ethnographic approach, as it focused on the experience of CRP among a specific ethnic group – Hispanic Latinos. Ethnography calls for a more immersed strategy within the population of interest.

Ethnographers must incorporate behavior, speech, and context into an understanding of meaning and, when possible, intentionally enter the situation to aid in data interpretation (Thomas, 1993). Conventional ethnography attempts to speak *for* another: describing an experience from another's cultural context. This study does reflect elements of culture, but as a primary methodology an ethnographic approach was not well suited. For example, immersing oneself within the cultural group of persons with CRP is not possible. Additionally, the population of Spanish-speaking persons with CRP was not a specific inclusion criterion, thus limiting the ability to incorporate language into the understanding of cancer pain. As the results report, there are dimensions of culture that are described. However, this is primarily a qualitative descriptive study.

It might also seem fitting to use a phenomenological approach as one could argue that any group is a culture of its own; therefore, exploration of a lived experience might fall under the category of phenomenology — the notion that "phenomena-appear through consciousness" (Thompson, 1990, p. 232). Phenomenology as philosophy assumes that the ordinary everyday experience of a given situation is best described by those living it, privileging the individual (Morse et al., 2001; Schwandt, 2001; Thompson). Phenomenology certainly has a strong position in nursing research to the extent that it helps in understanding personal (*emic*) needs of those for whom we care, even as it excludes a discussion of outside (*etic)* influences or perspectives (Porter & Ryan, 1996; Schwandt).

It is my assumption that confining the construct of CRP in a Hispanic/Latino population to only a personal level blocks from view other factors that contribute to the experience. As the inquirer it is important to listen for the nuances that represent such

influences. While both ethnography and phenomenology might be considered feasible methodologies, a more pragmatic method that is consistent with the previously described underpinnings is a qualitative descriptive method.

Sandelowski (2000) makes a provocative claim that researchers need to free themselves from forcing a qualitative study to fit into a design that may be perceived as a more complex method of inquiry. She suggests qualitative descriptive studies should not be considered crude, low-rung examples of qualitative design, as this assumes there is a hierarchical structure to qualitative endeavors. In fact, it is not uncommon to overstate the designation of projects as ethnographic or phenomenological when they are primarily descriptive (Sandelowski). She makes a case that within a descriptive qualitative approach it may be appropriate and even welcome to borrow principles of these other methods, which I have done. A challenge is in defining what constitutes a qualitative descriptive study in light of the multitude of other methods available, yet she attempts to do exactly that. It is her framing of qualitative descriptive methods that have served to guide this study.

There are two primary features of qualitative design that fit the current study. First, while there is, of course, an element of interpretation in qualitative design, the researcher does not "move far from or into their data" (Sandelowski, 2000, p. 335). All inquiry requires description and consequently requisite interpretation. In simply deciding what to describe lay the seeds of transformation. Sandelowski suggests that unlike other methodologies, qualitative descriptive interpretation resides close to the data, and analysis may be easily recognizable from previous literature or among and between researchers. The accuracy of findings was expected to resonate with others in the field,

with literature, or with the participants themselves. Researchers demonstrate rigor in that the summary of events and themes that evolve maintain descriptive and (to some degree) interpretative validity. This is evident by triangulating findings with other resources such as previous research, key informants, and other documentation that would support developing themes.

Second, in qualitative descriptive designs, no particular conceptual abstraction of the data is required. Sandelowski argues that qualitative descriptive designs are the least theoretical. I have described epistemology and philosophical foundations that have grounded this study, but no discreet theoretical framework was used to further organize data collection and analysis (Sandelowski, 2010). Rather, a general approach that sought to balance representation of individual and external factors that influence the experience of cancer pain and contribute to relief or perpetuate suffering guided data collection and analysis, with constant reflection throughout the process (Thomas, 2004).

Naturalistic inquiry as a method of data collection attempts to study something from its most natural position (Schwandt, 2001), which in this case is primarily from the position of the people with an experience of CRP. The situation of such inquiry is not to be contrived or in some manner manipulated. When conducted in a manner that is not forced or directed, such as might be imposed by a preselected framework, it is considered a naturalistic approach.

In her reframing of qualitative descriptive methods, Sandelowski (2000) left room to consider features of other methods that could be infused into an effective qualitative descriptive approach. Chapter II summarized aspects of culture as contributors to the CRP experience for Hispanic/Latinos, for example. Additionally, my position that

knowledge and meaning are constructed by external as well as internal factors makes implicit the need to examine these features with a critical lens. Rather than leave questions about whether these features were intentionally part of the data collection and analysis, I will briefly explain how both of these influences helped contextualize the description of CRP among Hispanic Latinos.

Shades of Ethnographic and Critical Influences on Experience

Participants' description of how culture was part of their experience of cancer pain was the focus of this study. Culture is broadly defined as the totality of learned behaviors and guidelines passed on through generations within a particular group — a blueprint of sorts, framing words and actions (Thomas, 1993). Helman (1994) conceptualizes culture as telling members "how to view the world, how to experience it emotionally, and how to behave in relation to other people, to supernatural forces or gods, and to the natural environment" (pp. 2-3). Leininger and McFarland (2006) suggest a more collaborative view of culture as being "the learned, shared, and transmitted values, beliefs, norms and life ways of a particular culture that guides thinking, decisions, and actions in patterned ways and often inter-generationally" (p. 13). Cultural influences include preexisting structures, religious influences, and symbolic artifacts unique to a given group. These descriptions of culture are often rooted in heritage and ethnic identity.

Culture is not merely a compilation of behaviors but rather an ever-changing construct influenced by both internal and external constraints and establishments. Moore and Butow (as cited in Moore & Spiegel, 2004) describe culture a bit differently — extending beyond groups, presenting a more explicit inclusion of structural influences.

They suggest that while culture is socially transmitted, it extends beyond beliefs and values to encompass social and political institutions and science. Crotty (1998) further describes the way in which culture aids our functioning through organization of symbols to direct our behavior and construct experiences. Ethnography, then, is not the methodology of the study, but ethnographic precepts contribute in ways that upbringing, local society, and institutional cultures influence experience.

To examine external factors that played a role on CRP experiences, assumptions and values embedded in healthcare institutions and providers were scrutinized. Structures can powerfully influence experience while being invisible to those inside, rather part of the usual fabric, situated within institutional norms. I felt it was important to examine external factors through a critical lens when possible; highlighting the subtle yet significant interpretations such factors might bring to data analysis.

In summary, this study explored CRP among Hispanics/Latinos using foremost a descriptive qualitative research design. Within this approach I sought to unite multiple sources of influence – individual meaning and expression – through discourse and behavior and broader societal, institutional, and provider-level factors. These features of experience mingle and contextualize, offering a fuller description of the phenomenon, advancing knowledge, and influencing practice (Sandelowski, 1993). The following sections frame the specific process of sampling, data collection, analysis, ethical considerations, and issues of quality, and describe the position of the researcher.

Sampling and Data Collection

The following section describes how access to the population occurred, the sample that was used, and the characteristics of those enrolled in the study —

specifically, inclusion and exclusion criteria. Both methods for data collection, summarized by type of information sought and a description of the sequencing, are outlined. An initial interview guide was developed and is discussed below.

Sampling

People with cancer-related pain are not found in one place. Within the structure of this type of study, spending time in the field means being in the facilities where they are treated. The inability within the local community to find a 'place' where Hispanic/Latinos with CRP are together is one reason that a primary ethnographic design was less feasible. When conducting naturalistic as opposed to conventionalist research, strategies for selecting a sample size are less easily articulated. Morse et al. (2001) recognize that there are many factors that may, in the end, decide a sample size in qualitative research. They argue, "The disciplinary purposes of research ought to inherently influence our understanding of sample size…." (p. 154), and without its thoughtful attention, those conducting qualitative research understandably risk scrutiny from the larger scientific community. Predicting how many participants are required is largely guided by the depth and breadth of the phenomenon of interest, influenced by the quality of the interviews, the preciseness of participant selection, and the fluidity between data collection and analysis. Sandelowski (1995) suggests that sample size can be guided by maximizing diversity within a phenomenon and/or demographic criteria or through adherence to a set of preselected criteria, narrowing the variables. I have chosen to maximize variation within a generally defined set of criteria, which is described below. In the end, the goal of purposive sampling should hold opportunities for gathering "information-rich" data from a selected participant profile (Sandelowski, 2000, p. 338).

Lincoln and Guba (1985) suggest that a sample size of 12-20 (when well defined) will often reach redundancy and deplete the possibility of new information emerging. Morse et al. (2001) refer to this as "sampling to redundancy" (p. 192). They offer a general framework to assist in articulating a sampling process for naturalistic design. Some of these elements have been selected to guide this study's purposive sampling plan.

Initially the researcher must identify the key elements for data gathering. In this study the primary data source came from Hispanic/Latinos with CRP. Secondary data sources included medical care providers, a traditional healer, family caregivers, medical records, and my field notes. Data were simultaneously collected from the primary participants and secondary sources as they became available. Successive phases of inquiry followed this general pattern:

1. Initial interviews addressed salient features that were based on the purpose and specific aims of the study.
2. As the preliminary findings emerged through concurrent analysis, refinement and more focused inquiry with the remaining participants occurred.
3. When new information no longer emerged, including subcategories that occurred, data collection from individuals with CRP ended. (More about the actual recruitment in Chapter IV.)
4. Initially I had hoped to conduct theoretical sampling with a small group to confirm findings and to fill in any gaps in the data. What happened instead was that themes emerging from early interviews were discussed with subsequent participants for reaction and confirmation. This approach was necessary due to the burden that another interview would have upon the

participants. (Again, this is more fully discussed in Chapter IV.)

Primary Sample

Convenience sampling was used for this study. Persons with a diagnosis of cancer and experiencing cancer-related pain who identified as being of Hispanic origin were the primary targeted group. No framework guided this study that would necessitate a particular type of cancer, just as there were no requirements for stage of disease. To focus on such characteristics positions the experience of pain as more narrowly attached to sensation and disease-specific factors, which is inconsistent with the theoretical underpinnings previously described. For this reason, any person who had a diagnosis of cancer and reported pain associated with that diagnosis was included. In order to maximize variation, taking opioids at the time of participation was not required (Lincoln & Guba, 1985; Sandelowski, 1993).

The interviewees resided in New Mexico and received medical care at one of a variety of cancer treatment centers located in the Albuquerque and Santa Fe regions of the state. A primary source of participant identification was through the University of New Mexico's NCI-designated Cancer Research and Treatment Center (CRTC). Currently, the CRTC cares for approximately 60% of the state's adult cancer population, caring for over 13,000 patients statewide. In addition, this center provides 6.8 million dollars in unreimbursed indigent care (UNM Cancer Center, 2014). Nearly half of these patients travel from outside the immediate vicinity, returning to their respective communities after treatment. More than 50% of the patients seen are ethnic minorities, primarily Hispanic and American Indian (UNM Cancer Center, 2014). Using the expanded statewide network of cancer centers for this study allowed access to individuals

residing in other areas of the state. Specific study eligibility criteria are described below.

Inclusion

- Self-identified Hispanic/Latino ethnicity
- A diagnosis of cancer (no limitations on stage or site) previously or currently receiving cancer therapy
- Current or recent experience of pain related to cancer or treatment lasting a minimum of 1 month
- Age range of 18 to 80
- English or Spanish speaking

Exclusion

- Concurrent unrelated chronic pain
- Additional physical symptoms that may or may not be related to cancer or cancer treatment (such as fatigue, nausea, cognitive impairment) that would render study participation unduly burdensome to the participant.

Secondary Sampling

Qualitative data collection seeks data from multiple sources in order to effectively achieve redundancy. According to Lincoln and Guba (1985), no data should be given serious consideration unless it has emerged from more than one source. In this study, additional sources of data were sought to compare and contrast with data from the primary participant findings (Morse et al., 2001). Secondary sampling represented:

- Healthcare – physicians who provide professional services to persons with cancer, noting their own expertise serving Hispanic/Latinos;

- Folk healers – Curanderas

Unexpected Sampling

It was not the intention of this study to interview family caregivers. On three occasions during the consenting process and initiating the interview, family members assumed their participation and became part of the study. I believed it would have been discourteous and insensitive of culture and relationship to ask them to leave during the interview. The primary participants seemed to desire their inclusion as well and this spontaneous nature of participation was welcomed by all. It is uncertain whether their presence hindered the primary participants from fully engaging and this could be a limitation of the study. Their participation, considered a protocol deviation, mandated reporting with the IRB. A waiver of unwritten consent was granted in order to include these family caregiver data in analysis (see Appendix B).

Data Collection

Steps in the data collection schema are described below. To begin, a summary of the steps is provided, followed by a more detailed description. These data sources are established to address both aims of this study. Table 6 outlines the data collection process and associated elements.

The Process of Recruitment and Obtaining Consent

Following approval from both the University of Utah Institutional Review Board (IRB) and the University of New Mexico IRB, clinic staff (nurses, social workers, navigators, and other supportive care team members) were oriented to the study aims.

Table 6

Data Collection Procedure

Steps	Components
1. Participant Recruitment and Consenting/Study Enrollment	a) Study overview provided at all recruitment sites to medical providers, clinic/chemo/triage nurses, patient navigators, staff meetings. IRB-approved flyers posted in public patient areas; presented at statewide cancer council; newspaper ad; sat in clinic lobby with recruitment sign; regular personal visibility at all locations; and ongoing contact with key gatekeepers throughout recruitment b) Screening for eligibility of prospective participants c) Consenting process (30-60 minutes/person) d) Initial review of medical record for demographic and disease data
2. Interviews (45-120 minutes)	a) Location selected by participant (personal residence or clinic site) b) Demographic data collection form completed c) Field notes compiled within 24 hours of interview
3. Intermediate Data Analysis	a) Simultaneous analysis for early code development while ongoing interviews occurred b) Interim findings incorporated into subsequent interviews including modification of the interview guide directed by these findings
4. Other Data Sources (Conducted simultaneously to participant interviews)	a) Interviews with key informants from the community b) Chart reviews/other relevant documents as their relevance emerged (analyzed separately)

Potential participants were identified and recruited during routine outpatient clinic visits. Patients could self-refer to the study from viewing flyers that were posted in public places within the treatment facilities, such as exam rooms, waiting rooms, and lobbies. Time was spent in lobbies advertising the study during busy clinic hours, phone triage nurses were targeted as another source of possible recruitment, and an ad was published in the health section of the local newspaper.

Participants meeting the study criteria who also agreed to learn more about the study, using the HIPPAA waiver, were referred to the investigator for further study description and possible enrollment. Many times participants self-referred by way of contact information on public flyers.

At that point, the investigator initiated contact with the prospective participant and described in writing and verbally information explaining the purpose of the study, procedures, and risks and benefits of participation. Upon confirmation of voluntary study participation, verification of meeting the study criteria was determined and interviews scheduled. The participants decided the location: coinciding with routine clinic visits or, if preferred, it was scheduled in their home at a mutually agreeable time.

Interviews

Interviews served as the primary method of data collection for this study. I would like to acknowledge that researchers are cautioned to avoid over-privileging such data and consider other sources of research data (Morse et al., 1998; Sandlowski, 2002). Roulston (2010) posits the interview be used in a way that is aligned with the researcher's epistemological assumptions about how knowledge is produced. It is from this position that interviews are structured, types of questions are chosen, and data representation is determined. For this study, an interview guide (with open-ended questions in alignment with the researcher's aims) was used to frame the interviews. However, the dialogue was allowed to move in whatever direction the interviewee wanted to go. As a new researcher, it was important to stay attentive to particular aspects of interviewing. Included were representation of self; how research questions are proposed and language used; the manner of probing, leading and pacing the interview; and finally how

clarifications are sought and the manner of responses to what is being shared (Atkinson et al., 2001; Bernard, 2006; Heyl, 2001; Madison, 2005).

My interview approach assumed that it is possible to develop a relationship with the participants even at the first encounter (Madison, 2005). As an oncology specialist for many years, with a large focus of my work being interactions with persons living with cancer-related pain, forming these connections is a natural and authentic extension of what I do; it is a norm in my practice. I do, however, recognize that I am an outsider on many levels; I am not Hispanic, Spanish is not my primary language, I do not have cancer, and I am a member of the participants' community only to the extent that I also live in New Mexico and work with people living with CRP. All of these realities may have interfered or interacted with the depth of sharing.

Researchers should engage genuinely, both in a subtle and deliberate manner (Heyl, 2001). It has been my experience that relationship can be built relatively quickly when there is sincere respect and when acknowledgement of one's experience is communicated. Mindful rapport is an approach to building relationship that can develop through the course of an interview (Madison, 2005). Some suggestions by Madison such as being able to listen attentively, engaging in positive naivetés (conveying that you are not the knower), and "patiently probing" were incorporated into the interview process. While the interview guide served a helpful framework, as topics arose that needed greater exploration, respectful deeper inquiry ensued (Madison, p. 33). Being comfortable and conveying a nonthreatening interview style are recognized by others and ease the interview process. Entering the field with such ease makes a difference. However, during the interview it is important to remember that while it might seem like a casual

conversation, it is not (Bernard, 2006; Sandelowski, 2002). The researcher keeps the conversation focused and then gets "out of the way; letting the informant provide information that he or she thinks is important" (Bernard, p. 216).

The interviews in this study lasted between 45-120 minutes and were digitally recorded. Sample opening questions for the interview and how they relate to the respective study aims are listed in Table 7. A complete interview guide for participants and key informants is found in the Appendices. The interview process relied on the art of creating a dynamic flow while staying focused on the interview aims. The preconstructed questions served only as a means for beginning the exchange. Even though the interview process was as reliant on the participants' direction as the researchers' in how the interview took form and developed, all research questions were addressed during the interview (Heyl, 2001).

Denzin and Lincoln (2003) suggest that researchers begin with less formal questions, gradually moving to more focused study-specific topics. They also discuss the particular challenges of how the interviewer presents herself, gains access, establishes trust, and builds rapport with participants. I introduced myself as an oncology nurse working for many years with people who have cancer and being accustomed to addressing the symptom of cancer-related pain. Yet, in this situation I am a novice researcher, only just beginning to appreciate the experience of CRP from their point of view. Acknowledging that I am trying to gain awareness and equally engaging in learning myself may help gain trust and establish rapport.

Language is an important part of the interview process. As Denzin and Lincoln

Table 7

Participant Interview Guide

Aims & Research Questions	Data Attainment	Method	Sample Questions
Explore dimensions of the CRP experience among Hispanics/ Latinos. *What characterizes the experience of CRP among Hispanics/ Latinos?*	Participants' personal experience of life in the setting of living with cancer-related pain	Interviews and Document Review	Many people with cancer experience pain. It is important in providing nursing care to people experiencing pain to understand, as much as is possible, what that experience is for the individual. I am most interested in hearing YOUR ideas, and I am here to listen and learn from your experience. 1. Can you talk about the pain you are experiencing (or have experienced) and what this has been like for you? 2. How do you talk about your pain to other people? 3. Can you share a little about how you learned what pain means and ways to express pain, growing up? 4. Can you talk about what this pain means to you? 5. Do you have worries or concerns about your pain? 6. Can you talk about ways you deal with your pain? a. What ways do you try to help the pain get better? 7. Can you talk about how your culture, family, or spiritual practice influence your experience of this pain? 8. Is there anything about your culture that might influence your experience of pain or how you feel about pain? 9. What is the *worst part* of having pain? <u>Things to watch for during interviews:</u> Folk remedies for pain; Any ways your culture/upbringing helped you address your pain? Or got in the way of helping with your pain?
Describe how structural and provider-level factors influenced the experience of CRP among Hispanic/Latinos *What external factors influence the experience of living with CRP among Hispanics/Latinos?*	The barriers, obstacles, and other factors in the environment that influence living with cancer-related pain.	Interviews and Document Review	1. Have there been things that have interfered with or affected your pain experience or taking care of your pain? 2. How do other people react or respond to your pain? 3. How would you describe how your doctors, nurses, or pharmacy workers talk with you about your pain and medications? 4. Can you talk about ways the healthcare system influences your experience of pain? 5. What do you see as getting in the way of best taking care of your pain? 6. If you could give advice to either someone with cancer or to your health care providers, what would you like them to know? (either or both groups) 7. Are there any other issues you would like to share or things you want me to understand related to our discussions? 8. What did I not ask you that I should have?

(2003) state, "the use of language, particularly the use of specific terms, is important in the creation of a 'sharedness of meanings' in which both the interviewer and the respondent understand the contextual nature of specific referents" (p. 86).

Establishing a shared understanding of key constructs as well as clarifying the use of language that might be unfamiliar to the researcher or the participant were important elements of conducting the interview and interpreting interview data. For example, describing what was meant by experience of pain and providing information on why the study focused on Hispanic/Latinos became a helpful way to begin the interviews and develop common understanding.

Potential Threats of Interviewing

Using a constructed set of questions is not considered essential to interviews but may help new researchers. What is considered essential is a spirit of curiosity, humility, and true interest (Madison, 2005). Madison further summarizes many key features for researchers to consider when conducting interviews. Included are considerations of threats that can affect those interviewed. Referencing Gordon's Model (Madison), Madison addresses these threats. One dimension of interaction that can be threatened is referred to as *Degree of Etiquette*. Here the participant may limit the extent or type of information disclosed because of gender, ethnicity, age, cultural politeness, or other habits that somehow interact with perceptions about the researcher. Factors that may impact these perceptions might be where the interview is conducted, how questions are presented, and how the participant perceives her or his positionality relative to the researcher. To limit these forces, participants in this study chose the interview setting - either their own home or during a scheduled clinic appointment. Requesting that the

participant make this selection was intended to enhance their level of comfort, thereby minimizing some of these factors or perceptions.

A second potential threat to the interview experience is related to *Degree of Trauma*. It is likely that a discussion of pain becomes intertwined with the underlying disease and life-threatening nature of a cancer diagnosis. Exploring experience around such a topic holds the potential for emotional responses. It became important to remain empathetic and present as they spoke of sensitive and emotional aspects of the pain experience. I have many years of experience with the intimate nature of such conversations and remained intentional in how I communicated through body language, choice of words, depth of exploration, and empathetic responses (Madison, 2005).

In summary, although there is variation in guidelines as to the most salient and effective means to conduct interviews, Heyl (2001, p. 370) outlines four commonly described goals. The interview process for this study was guided by these ambitions:

1. Listen well and respectfully, developing an ethical engagement with the participants at all stages of the project;
2. Acquire a self-awareness of my role in the co-construction of meaning during the interview process;
3. Be cognizant of ways in which both the ongoing relationship and the broader social context affect the participants, the interview process, and the project outcomes; and
4. Recognize that dialogue is discovery and only partial knowledge will ever be attained.

Field Notes

A final, yet essential, component to the interview is capturing the various types of nonverbal means of communicating. Field notes record such findings and are considered central to accurately reproduce the data at a later date (Lincoln & Guba, 1985). Denzin and Lincoln (2003) provide a useful frame for categorizing such data. I started with review of the whole corpus of my field notes as they evolved over time, including observation during the interviews with both the primary study participants and key informants (healthcare providers). Using an open-coding style, all ideas and findings are represented, generating reflections without attention to specific aims (Emerson, Fretz, & Shaw, 2011).

Within hours of completing each interview, field notes were recorded either through a journal or via digital recording. Both means were later transcribed and became part of data analysis. I was able to capture some of the unseen shades of the interview experience not evident through a transcribed interview (Schwandt, 2001). Attention was paid to how body movements, posturing, and interpersonal space were used, and pitch, volume, and quality of voice were integrated into these notes. Aspects of the environment, whether using a clinic room or a living room, were described.

Field notes can be managed much like other data sources in qualitative research (Bernard, 2006). I followed a specific approach to writing the field notes, which involved an initial write-up after the interview, followed by a careful review of these notes side by side with the audio recordings. Bernard outlines three types of field notes:

- Methodological – the technique of data collection
- Descriptive –data from watching and listening

- Analytic – personal ideas of how factors are playing into the phenomenon; how culture is influential

The descriptive approach was used to reflect what I saw within the space and during interactions between myself and the participant and between others who might have been present. The purpose of taking descriptive field notes was to capture aspects of the field setting that would not be recognized through recordings. My field notes reflected quite precisely what I observed physically in the environment: the neighborhood, the layout of the home, including pictures, furnishings, and the use of space, sound, and smells, for example. In addition, behaviors, facial expressions, physical contact, distancing, roles, and interactions with others were captured.

In summary, the interviews were guided by principles intended to maximize relationship building, trust, positioning of subject as the authority, and allowing for a conversational style while staying focused on the research aims and questions. In addition, taking field notes and using digital recordings captured both the fidelity and structure dimensions of interviews (Lincoln & Guba, 1985).

Additional Data Sources

While individuals with CRP served as the focus of the data collection and analysis, other research data were desired to develop a fuller understanding of the Hispanic/Latino experience. Considered to be relevant additional sources of data, are observation, examination of documents, other individuals that may provide another view of a phenomenon, and artifacts (Sandelowski, 2002). In order to explore the impact of external factors on cancer-related pain, expanding data sources beyond the primary participants was necessary (Bowen, 2010; Denzin & Lincoln, 2003; Richardson, 2003).

Key informant interviews, caregivers, and medical record data were included as a means to augment the primary interviews, providing additional information that could contribute to the study aims.

Healthcare Providers

Additional sources of data were sought, occurring in tandem with the primary participant interviews. For this study, I sought to interview healthcare providers, contributing to perspectives on CRP in this population. Three interviews were conducted to capture their perspectives on what, if any, cultural factors might influence care for this population. A description of these providers is presented in Chapter IV.

Medical Record Data

Data were collected pertaining to clinical variables such as type and stage of cancer, type of treatment, current medication history, and co-morbidities, characterizing the sample population. To explore how the participant discourse around the experience of pain might (or might not) be supported by written text, I sought to determine the ways providers were addressing pain and what the providers were talking about. Participants consented to allow the researcher to review and collect data elements that pertained to disease characteristics and documentation of assessment and management of pain.

The description of this pain discourse was examined from the time of most recent pain care, extending back to the preceding three months of medical care. For example, to explore features of the first research aim, it added depth to note who was formally engaging in the pain assessment and treatment elements and how they recorded these details. A guide was used to query the medical record. Table 8 summarizes the

Table 8

Medical Record Abstraction Guide

Research Aim	Rationale	Elements
Explore dimensions of the CRP experience as they are described by Hispanic/Latino participants.	How the healthcare providers construct the experience of an individual's cancer-related pain	1. Who is talking about the person's pain in the medical record? 2. What means are used to assess the person's pain? a) Physiologic Descriptors b) Psychosocial/Affective Descriptors c) Intensity Rating 3. What means are used to manage the person's pain? a) Pharmacologic b) Nonpharmacological?
Describe participants' perspectives of how local, institutional, and provider-level factors influence the experience of CRP.	The barriers, obstacles, and other factors in the environment of care that influence living with cancer-related pain.	1. What evidence is recorded that addresses possible system barriers, or misconceptions, or lack of cultural awareness related to the discussion and treatment of pain?

components of the chart abstraction as it pertained to each aim.

The second aim intended to examine external influences such as provider-level factors that impact the pain experience. One source of data related to this aim was to analyze documentation for alignment with standards of care and record what themes were developing from the primary interviews. This study proposes that the cultural systems of care that guide healthcare are important elements in effective care. The extent to which documentation reflects pain assessment and management serves as a symbol to its position in overall care.

In summary, the rationale for including the healthcare provider interviews and medical record findings was not to create a multivocal analysis of the experience of CRP but rather to explore how perspectives influence the individual experience and context of those with CRP. Often the interview itself can be privileged over other research data

categories. I would say that while the interview is a central feature of this study, I collected data that were available from providers, family caregivers (described above), and medical records, gaining rigor and serving as a means of confirming and validating findings (Meadows & Morse, 2001; Sandelowski, 2002). Extending data outside of the individual telling of experience creates opportunity to further illuminate external factors that influence the experience, which is part of the second research aim.

Participant Demographic Data

A basic demographic data collection tool was used in this study to capture the following: age, gender, family income, preferred language, education, religion, years living in the United States, work status, marital status and other identified support systems (Appendix A). It is important to acknowledge the controversy around acculturation measures and why I chose not to include this as part of my data collection. Measures of "taking on" the host cultures' norms and practices are common in much of the research with diverse populations (Im, Ho, Brown, & Chee, 2009; Palmer, MacFarlane, Afzal, Esmail, Silman, & Lunt, 2007). Negy and Woods (1992) illuminated inherent flaws in the practice of routinely linking acculturation with various health outcomes or behaviors. Several studies in their review demonstrated many of the factors considered reflective of acculturation; gender role attitudes, decision-making, and other traditionalism actually co-varied or interacted with socioeconomic status (SES). When SES was controlled for, these factors demonstrated a weaker relationship with various outcome variables. The degree of centrality of family social support and networks and reliance on the nuclear family as the primary source of support among Mexican-Americans subgroups, for example, were predicted by SES rather than acculturation.

Perceived support, in fact, was unchanged by level of acculturation and seemed to be a single distinctive characteristic of Hispanic/Latino familialism. Although Negy and Woods acknowledge studies that found the role of family among Hispanics changes with degree of acculturation, they suggest that researchers have not consistently accounted for the role of SES and how it may co-vary with acculturation.

Taking a sociopolitical view, others have taken a candid look at the underlying assumptions of assimilation or acculturation (Lara, Gamboa, Kahramanian, Morales, & Hayes Bautista, 2005). To acculturate is to leave behind or unlearn culturally derived behaviors in exchange for the preferred dominant core cultural norms of the largely White Protestant, Anglo center. To acculturate is to accommodate into an improved life - a life that is considered better than one's origins.

More recently, Lara and colleagues (2005) further substantiate findings of Negy and Woods (1992) on acculturation and links to Hispanic/Latino behaviors and health outcomes. They suggest that acculturation is too complex and not well developed, with evidence demonstrating a positive, negative, or no effect, depending on the particular study. Several of the reported studies suggested an interaction with SES and education rather than acculturation on such variables as health promotion and screening behaviors.

Building on the argument that measures of acculturation are tenuous at best, Zambrana and Carter-Pokras (2010) explicitly contend that to not account for economic and structural factors when evaluating Hispanic/Latino disparities leads to flawed research. Socioeconomic position (SEP) often remains naively in the shadows when making such associations. They highlight studies demonstrating a stronger effect of SEP than acculturation on healthcare use among Latinos, suggesting that acculturation often

acts as a proxy for SEP. Embedded within lower SEP likely lives structural inequities, low-resource access, and low or insufficient provider cultural competence. These factors are often not identified when the focus is on acculturation.

As I have considered the recent critique of acculturation measures from historical and economic perspective, it calls into question the rationale for such an appraisal within the framework of this study. The notion of measuring a construct such as acculturation from this lens was inconsistent with the aims of my study.

Data Organization

The majority of analyzable material came from taped interviews transcribed by an independent transcriber. Computer application continues to evolve and expand for analysis of qualitative data (Fielding, 2001). Considered an "art" rather than a technique, analysis is now able to access technological tools for more efficient data management. In qualitative work, when using computers the researcher is cautioned to not relinquish the interpretation to technology. Fielding reminds the researcher that traditional means of manually coding and segmenting data are equally at risk of abuse. With this awareness in mind during analysis, a computer program was employed to retrieve text, code, and manage data.

Atlas ti (v7) was used to house transcripts and provide structure for data analysis and synthesis (Muhr, 2012). Only basic features were employed, such as cataloging codes, memos, and quotations that would later be extracted as examples of developed themes. The software proved quite useful in efficiently recalling specific detail that had been categorized, as I needed to frequently return to the body of all of the interviews. Atlas ti (v7) also served to quickly store linkages, providing a visual model throughout

analysis. Descriptive statistics were used to summarize demographic data.

Analysis and Establishment of Themes

Results of qualitative descriptive studies are often presented as themes. This study evolved from within the framework of thematic analysis, staying aligned with the study aims (Gladden & Cook, 2003). I would like to take a moment to talk about the concept of theme in qualitative studies. DeSantis and Ugarriza (2000) examined the use of the term "theme" in such research designs. I have adopted a description of what theme means in this study, based on their review. A theme in the context of this study reflects a broad unit of thought that links various categories extracted through the process of analysis. Morse and Field (1995) further describe themes as related threads that, through careful analysis, can be seen across multiple interviews. Themes in this study are intended to reflect the spirit of meaning or experience (DeSantis & Ugarriza). The specific steps that guided analysis are delineated in the section below and summarized in Table 9.

The first step was to determine accuracy of the interview transcription. Each digitally recorded interview was compared for exactness and for missing or incorrect wording. Recordings were remarkably well-transcribed with only occasional missing content that was not recognized by the transcriber. Correcting these missing data was simple as I was able to recall the dialogue and context from the digital recording and fill in the missing or misunderstood wording.

Data analysis began with the first interview, informing future interviews and guiding questions (Cooper, 2010; Roulston, 2003). A read-through without attempts to

Table 9

Summary of Steps in Analysis

1. Confirm transcript integrity – concurrent review of written transcript and digital recording
2. Individual transcript full reading without editing – free reading
3. Individual line-by-line transcript read - develop keywords and codes
4. Modify interview questions based on early emerging generic categories
5. Individual transcript reading - formulate generic categories
6. Add data into existing categories and create new categories as seen
7. Edit or exclude unrelated interview material when outside of the study aims
8. Evaluate categories for similarity – collapse and rename as appropriate
9. Review each transcript where categories were combined/changed - confirm alignment within the context of the data
10. Develop themes and associated categories within a theme

label was done with each interview prior to indexing or cataloging (Jones & Watt, 2010). This process of forgoing ordering allows the researcher to return and re-engage with the context and the conversation (Jones & Watt). It was during this stage of analysis that the associated field note was opened and concurrently reviewed. In the early analyses, I found myself remembering details of the experience that were not captured in my field notes. For this reason, I developed a strategy of parallel review of the field notes, adding associated recollections as they were relevant to the study aims. I was mindful to not remove or otherwise edit existing field note documentation, and analysis of field notes did not yet occur (Emerson, Fretz, & Shaw, 2011).

The original hope was to return to participants for a second interview, intending to actively seek negative cases or explore saturated findings in a more robust explanatory manner. Because there was a significant participant burden in conducting a follow-up interview and the fact that several of the participants died during the course of the data collection, returning to the participants for a second interview did not occur. Rather,

using a constant comparative approach, data collected from each interview were analyzed, and as early data grouping took shape, findings were integrated into subsequent participant interviews (Lincoln & Guba, 1985). With each new interview salient data elements were evaluated for suitability with developing clusters of data, and if they did not fit, a new category was established. Again, there were no predetermined themes or groupings; as categories of meaning developed they formed the beginning stages of theme formation.

It was important to maintain a degree of cooperation between the participants and myself, recognizing that multiple meanings exist in any interpretation (Graneheim & Lundman, 2004). This approach to confirming findings, while considered not ideal by some (Meadows & Morse, 2001), is considered an acceptable alternative to member confirmation by others (Heyl, 2001). Validating and restructuring findings is critical to deepen engagement and exploration, and assessing mutual understanding or congruence of the data interpretation is recommended (Atkinson et al., 2001). Participants were asked to react to categories that I was forming to describe their experiences as Hispanic Latinos experiencing CRP. These open reflections generated confirmation and further data into the particular ideas and categories. An example of this related to the notion of ways of coping – learned behavior from childhood. In subsequent interviews, as the interviews came to a conclusion, I shared this observation and asked for their reaction. A response to this was: "*Oh yea, I think it's a cultural thing. With men it's a macho thing. We don't say we're in pain maybe because your mom says 'ah, go take a ginger…"*

Final Interview Analysis

The next step in data analysis was indexing. Madison (2005) suggests coding and logging as a means of organizing and separating the complex and expansive data. Specifically, she defines this as a "process of grouping together themes and categories that you have accumulated in the field" (p. 36). Madison does not ascribe to a particular style of analysis such as content or thematic; instead, she offers a stepwise framework for analysis. I have summarized and adapted her framework for this study. The modified Madison process I used in analysis of quotes and codes to arrive at themes and categories follows:

1. Initial data were categorized by type: participant, field notes, providers, and caregivers.
2. Initial "pieces of patterns" and like-minded threads developed within each code family and were examined within and across categories (Leininger, 1985, p. 61).
3. Meaningful units of data were examined for uniqueness, commonality, or possible irrelevance to the study aims.
4. Category comparison yielded refinement and consolidation.
5. Broader more universal themes developed from the subthemes or categories.
6. Categories across themes were examined for linkages and relations
7. As final themes and categories became stable, the transcripts were re-examined a final time to confirm the analysis. Returning to the text has the potential to bring new ideas, details, and interpretation to light. (Roulston, 2010).
8. Themes were reviewed by my dissertation chair, Dr. Lauren Clark. This feedback served as reflection and inquiry, providing questions and offering feedback in terms

of evolving thematic categories. To address reliability, part of this exercise served to clarify how coding categories were defined and to assess for any missing descriptions.

Analysis of Additional Data Sources

The primary participant interviews were considered the central source of data, with additional data sources integrated as a way to confirm, dispute, broaden and deepen the understanding of CRP in Hispanic/Latinos. Field note analysis as well as the healthcare provider interviews and caregiver data followed a similar pattern of analysis however these sources of data were analyzed at the end of interviewing and preliminary thematic development. In the end, as these findings aligned with the primary thematic categories, they were then combined but distinguished as field notes, provider data, or caregiver data.

Field notes were analyzed after the primary interviews were completed and major themes and categories developed. Coding of notes followed the same steps, as did the interview transcripts, using Atlas ti to catalog and organize themes. Individual interview field notes remained part of the Field Notes cluster and were not merged into their respective interview transcript, for example. Again, using field notes as part of data is not uncommon in other disciplines (Bernard, 2006).

Medical record data were not entered into Atlas but rather collated by category of findings that followed the data collection guide (Table 8). Descriptions of pain found in the medical record were compared and contrasted to how participants talked about pain during the interviews. The charts were also mined for what was being recorded about pain management. These comparisons served both to strengthen thematic categories as

well as validate divergence or identified gaps. Similarly, documentation of pain assessment was contrasted with standard EBP guidelines for pain assessment. These data were summed, and descriptive analysis was used to present the findings. Discrepancies, gaps, or congruence contributed to thematic findings.

Synthesis of Data Analysis

Data analysis began as data were still being collected. There was a synergy of both collection and analysis that reciprocally shaped the process (Morse et al., 2001; Sandelowski, 2002). New data from the interviews and later from caregiver texts, healthcare provider records, medical records, and field notes continued to reconstruct themes that had begun to take shape from early interviews. Using Atlas ti, each data source was established as a code using the Code Manager. These individual codes were clustered by type and color-coded for easy identification. For example, both primary participants (categories in yellow font) were examined side by side with a similar code from the professional caregiver (font colored red). In this way the separately assembled data were lined up and reviewed for convergence, divergence, and overlap. During this review some codes were linked to other codes. During this final step in analysis, categories were validated for congruence and merged when appropriate. Where there was not congruence the codes stood independently by data source.

Ethical Considerations

Any research that addresses aspects of experience with a life-threatening illness poses the risk for emotional discomfort. It was critical in conducting this research that participants retain full confidentiality for decisions regarding participation. Two

significant aspects of this population posed additional potential burdens – living with pain and possibly being of marginal health as related to the stage of their cancer illness. These factors were given consideration as participants were approached for enrollment in the study. In addition, both the University of New Mexico Health Sciences Center and the University of Utah institutional review boards (IRB) scrutinized the study plan. IRB approval was granted at both institutions.

All participants received full disclosure on the purpose, potential emotional risks, and protection of rights and privacy through the informed consent process, and they reserved the right to judge for themselves the degree of risk they were willing to take on behalf of furthering scientific discovery. Consideration for the degree of burden placed on these individuals was made. For example, interviews did not go beyond a reasonable length based on fatigue and other endurance issues, and maximal effort was made to minimize stressor complexity related to such things as schedule and travel restrictions. As noted previously, many of the participants became quickly more ill and were not able to participate in a second interview; in fact, many died during the course of data collection. The burdensomeness of returning was greater than the benefit. Alternative means to confirm findings was sought.

Digital audio recordings and any identifying paperwork (such as the master list of research participants) were stored in a password protected computer file on a secure University of New Mexico computer in the researcher's private office space. Consent forms were stored separately from all other data files in order to maintain confidentiality or to de-identify the data. During interviews caution was used to not use names of individuals or otherwise risk identity of participants or healthcare providers. Names were

not included in the creation of written transcripts, instead pronouns or nouns were used (he, she, participant, spouse, for example). Pseudonyms were used to de-identify individuals, locations, and facilities when results were presented. Description and characterizing of the healthcare providers were limited in order to protect their identity in the community.

Issues of Rigor

I would like to momentarily return to the notion of balance in data collection. This study has privileged the interview as a major focus of data. While the sample (as described in Chapter IV) was not as large as initially desired, other sources of data were used to augment or triangulate findings from the primary interviews (Tappen, 2011). Several forms of triangulation are described in the literature, but for this study methodological triangulation was conducted (Patton, 2002). This strategy accessed multiple forms of data such as primary interviews, healthcare provider interviews, family caregiver interviews, field notes, and medical record abstraction.

Reliability and validity are the language of quantitative research, yet these principles are also applicable in qualitative approaches. I situate these constructs as they pertain to this qualitative descriptive study but have done so from the position that reducing qualitative analytical processes to a list of technical procedures does not confer rigor (Barbour, 2001; Sandelowski, 1993). I have attempted to engage in good scientific rigor, attending to many features of trustworthiness and ultimately yielding an accurate and meaningful description of the experience of CRP among Hispanic Latinos.

Reliability is fundamentally a desire for reproducibility of measurement and signifies a more positivist paradigm (Golafshani, 2003). Measurement is objective and

quantifiable and assumes the need for demonstrating consistent representation over time. Qualitative inquiry presumes research findings will be unique and contextually situated. Thus there is less need or desire for this sort of stability in measurement. Sandelowski has suggested that efforts to achieve reliability in qualitative work can undermine validity. She challenges the assumption that reality is external, consensual, corroboratory, and repeatable (1993). Repeatability is not an essential property in itself and, in fact, quite difficult to attain. Lincoln and Guba (1985) suggest that reliability in qualitative work is more reflective of dependability and can be enhanced by various methods. Strategies to achieve optimal quality in qualitative investigation are used for the purpose of engendering understanding as compared to the purpose of explaining, which is more common in quantitative research (Golafshani).

In contrast to the less germane notion of reliability, maximizing the development of a construct being explored is an important attribute of qualitative research. Several more precise descriptions of what is traditionally know as validity exist in qualitative study such as quality, rigor, trustworthiness, credibility, and confirmability (Davies & Dodd, 2002; Golafshani, 2003; Lincoln & Guba, 1985; Morse et al., 2001; Seale, 1999; Stenbacka, 2001).

Dependability, for example, was addressed by way of making the research process and data collection procedures transparent (Bloomberg & Volpe, 2008). I have been transparent in my research process such that reproduction would be feasible if desired. A description of the steps of data collection, analysis, and exemplars (presented in the results section of Chapter IV) are provided with a substantial audit trail constructed throughout each step of the project. Trustworthiness as a means to quality contains

elements of confirmability. Chapter V has captured ways that the data coalesced and resonated with other similar findings, strengthening confirmability (Tappen, 2006).

I would like to posit a perspective held by some researchers that the well-known strategy of member checking, used to strengthen confirmability, is not always desired or believed to accomplish what it intends. Sandelowski (2002) challenges the exercise of returning to participants to validate findings, suggesting that results are often ambiguous and arise from the confines of a discreet social interaction. Stories and recollections themselves change over time and situation (Sandelowski, 1993).

Sandelowski (1993; 2001) and others claim that the members themselves are not always the best judge of what a valid research account is, and may not recognize their individual contribution presented back to them as summarized findings (Barbour, 2001; Morse et al., 2001; Tappen, 2011). When returning to participants, they might not recall what they said, regret or have changed their perspective, or perhaps want to please the researcher and simply agree with the findings (Sandelowski). Findings come from a social interaction and the next occasion for such an interaction will be different.

In an effort to practice good science, I sought clarification and elaboration during interviews (Sandelowski, 1993). I summarized findings from past interviews to current participants and solicited feedback or reactions. According to Sandelowski, individuals look for their story, and researchers strive for multiple truths while attempting to uphold fidelity to the individual stories. Further discussion of quality is found in Chapter V as part of the discussion of limitations.

Researcher's Assumptions and Personal Perspectives

At this point it seems fitting as part of the discussion of quality, while remaining true to the standard of reflexivity, to describe my viewpoint as I began this research project. It is important to explicitly recognize how my positionality came from both my personal and professional tradition and contributed to expectations, the interview experience, interpretation, and ultimately the generation of new understanding (Morrow, 2005; Sultana, 2007). Although themes emerged, some element of interpretation was subject to my standpoint, assumptions, expressions, and experience. I must also be explicit that I am a novice researcher with limited experience in data interpretation. It was imperative that I access the multiple resources available to assist in that process as well as consult with experts in the field. Roulston (2010) exquisitely reminds us of the imprinting that happens to research projects as an outgrowth of the complex interactions of researcher and interviewee; as researchers, we must recognize the contribution of our social location, language, status, age, and gender among other important characteristics that inform the interview and interpretation.

I have spent the better part of 25 years practicing nursing in a variety of settings within the specialty of cancer care in the western part of the United States. Although I've provided care for persons of many ethnic identities, Hispanic Latinos remain one of the largest subsets of people in my care across all settings of my practice. Many of the cultural practices common among persons self-identified as Hispanic/Latino are familiar to me and easily woven into my nursing care. One such example is the desire for multiple family members to participate in care and be present in the sense of "convivir," or being with, coexisting with another as an offering of support. I have been witness to the

suffering and burden imposed on individuals, families, and support networks that often accompany cancer-related pain. Over the years, I have seen the many levels of obstacles that are imposed on persons through systems, regulations, and cultural bias as they relate to CRP and have tried in my own right to be a voice of change in this regard.

I am aware of my physical presence as a White middle class woman and how this might have imposed certain assumptions onto the developing relationships I formed during data collection and analysis. Taking that into account, I also consider that having an outside standpoint, while an inside familiarity with the issue of CRP and encounters with persons with cancer, could create grounds to engage participants.

As I embarked on this research project, I was willing to reflect on the difficult question: "What do I see as my own gain?" To be able to illuminate what I feel are unnecessary and ineffective barriers to care would be gratifying at this point in my career. To be able to bring voice and articulate through the scientific process what seems congruent to my practice would be professionally meaningful and consistent with my philosophy. It would be equally meaningful to discover aspects of people's experience that are not necessarily harmonious with my assumptions, and they would be reported as well. It was my goal to add to the growing understanding of a particular experience of CRP; to bring to the surface the multiple layers that contribute to such an experience – layers that are not as readily uncovered.

Limitations

Descriptive qualitative researchers strive to illuminate features of a phenomenon from the perspective of the participants – an *emic* lens, from the inside (Porter & Ryan, 1996). The reality that I am outside, neither a cancer survivor experiencing pain nor

Hispanic/Latino, with my own theoretical and cultural position could be seen as a strength as well as a limitation. I have discussed the ways my perspective and position might have influenced the interviews and the analyses, but I am hopeful that with awareness and reflexivity I can use some of these standpoints as strengths, merging both the emic perspective of the participants with the awareness of some of the etic influences on these experiences.

Additionally, the potential for respondent burden did prove to impact the initial desire for a second interview. All efforts were made to reduce the burden on interviewees while maximizing the richness of the encounter. No disruption occurred during the interviews due to participants' health or discomfort. However, due to the advanced stage of illness and the demand placed on participants for another interview, second interviews were forfeited. In the end, there were only two possible participants who could have participated in a second interview. One had recently had surgery for recurrence and the other had traveled to her home country due to a family member's illness. The remaining participants became progressively sicker, experienced more severe pain with advanced disease, or subsequently died.

Summary

This chapter has addressed the rationale for the study design and methods in examining the experience of CRP among Hispanics/Latinos. A descriptive qualitative design with underpinnings of a constructionist epistemology, with ethnographic tones and critical inquiry, guided the interviews and data analysis.

The participants and data collection process have been described, with sample interview questions presented. The analysis processes have been outlined. I have

attempted to address issues of quality and to reveal my position as a novice nurse researcher in an effort enliven the transparency I hoped to maintain throughout the study.

The next chapter describes the analysis and findings related to aspects of what constitutes an experience of CRP among this sample of Hispanic/Latinos. It also presents how the themes and categories align with the study's aims and with each other.

CHAPTER IV

RESULTS

The results are organized beginning with a description of the participants. Following this, the environment is contextualized, describing where the interviews occurred and other aspects of the interviews and data collection that are not obvious from the interview data. The next large section details the themes and categories as they developed from the primary participant interviews. Data from secondary sources follows and I discuss how these findings aligned with the main themes and categories. The medical record data are then reviewed in an effort to describe how the healthcare providers' documentation on pain may expand understanding of both study aims– reflections on the pain experience and any contributing structural or provider-level factors. The chapter concludes with a summary of the findings and how they align with the research aims.

Primary Participant Characteristics

There were 14 primary participants (individuals with CRP). Table 10 describes key characteristics of the primary sample. All of the participants spoke English with two reporting Spanish as their primary language, but they were proficient in English and able to comfortably participate in the interviews. The majority (71%) stated they were descendants of Mexico, yet all were second generation New Mexicans. Two preferred to

Table 10

Primary Participant Demographic Characteristics

Demographic Features (n=14)		*n*
Ethnic Heritage	Mexico	12
	Latin America	2
Years in United States	Native	13
	15 yrs	1
Primary Language Spoken	Bilingual	5
	English	9
Religion	Catholic	6
	Christian	4
	No Preference	4
Gender	Female	10
	Male	4
Age	Average	55
	Range	25-75
Marital Status	Single	4
	Married	10
Number of persons in the home	One	2
	Two	8
	Three	3
	Four	1
Annual Family Income	<20,000	3
	30-49,000	5
	50-60,000	4
	> 60,000	1
	No Reply	1
Working Status	Unemployed	2
	Disability	3
	Part time	2
	Fulltime	3
	Retired	4
Education Level Completion	< High School	2
	Graduate/GRE	8
	Some College	4
Health Care Coverage	State Medicaid	5
	Medicare	5
	Private	4

identify themselves of Spanish heritage but with their immediate ancestors having come from Mexico (They were also second generation). Many people of Spanish heritage are from Mexico as a result of Spanish colonialism of Mexico. One participant was of Cuban descent but a second generation resident of New Mexico and the final participant was born in Chile.

Less than half described themselves as Catholic (43%); others identified themselves as Christian (28%); with as many selecting no preferred religion. Most were women and married (71%, respectively). Only one participant lived alone; all others resided with family members and/or a spouse. The mean age was 55 with a range from 25-75 years. In terms of working status, there was representation from most categories with some retired, on disability, or working full or part time.

Interestingly, this sample was also diverse in terms of cancer diagnosis, with no particular diagnosis overrepresented. For example, as reported in Table 11, in addition to common sites of cancer such as breast and lung, there were participants with sarcoma, brain, cervical, and melanoma, reflecting that pain is present across cancer diagnoses. More commonality was found in the stage of cancer with the majority having more advanced stages at the time of interviews. All had received some form of treatment and the sample was split in terms of those currently undergoing treatment versus those who had completed treatment. The majority had no comorbidity.

Secondary Participant Description

I will only provide a broad description of these participants as more detail will put their confidentiality at risk. I was only able to interview two medical practitioners and one traditional healer. One physician was a primary care family practice provider with a

Table 11

Primary Participant Clinical Characteristics

Features of Illness/Treatment (n=14)		*n*
Diagnosis	Breast	4
	Lung	2
	Colorectal	2
	Lymphoma	1
	Osteosarcoma	1
	Cervix	1
	Leukemia	1
	Brain	1
	Melanoma	1
Stage of Disease at Time of Study	Stage I	2
	Stage II	2
	Stage III	2
	Stage IV	7
	Unknown	1
Past Treatment	Surgery	11
	Radiation	10
	Chemotherapy / Biotherapy	12
Current Treatment	None	5
	Radiation	3
	Chemotherapy/ Biotherapy	6
Pain-related Medications		
	Immediate Release (IR) oxycodone	10
	Sustained Release (SR) oxycodone	8
	IR morphine	7
	SR morphine	6
	Gabapentin	6
	Dexamethasone	3
	Hydrocodone	2
	Tramadol	1
	Pregablin	1
Co-morbidities		
	Light-chain neuropathy and ARF	1
	Arthritis (mild)	1
	Anxiety/Depression	1
	Hypertension	1

subspecialty in palliative care. The other was an oncologist. Both collectively had over 60 years of clinical practice within their respective fields and both had many years of addressing CRP in their population. Both providers were bilingual and perceived themselves to have a lot of experience working with Hispanic/Latinos.

The other provider interviewed was a traditional folk healer: a curandera. This individual had more than 10 years of clinical practice working with many types of individuals, mostly Hispanic/Latino but with a wide variety of conditions and inquiries. She came from a family that had lived in another part of the state for many generations and considered themselves to be of Mexican descent. She was bilingual and felt a strong foundation in working with Hispanic/Latinos, some of whom had CRP.

Family Caregivers

Three participants were family caregivers who serendipitously participated in the interviews. They were not screened for any demographic information as they were not part of the study, and I can only report their relationship to the primary participant. One individual with CRP had a sister who lived with her and provided day-to-day care. It was clear that the sister had a strong desire to talk about the topic of her sister's pain but was distracted by activities in another room and came in and out throughout the interview.

One of the other caregivers was a female partner of a gentleman who had CRP. They had moved in together since his illness progressed and had been in relation for many years. They were not married and did not have children together. The last caregiver was a male partner of a woman with CRP. They had grown up together in a small rural community in a northern part of the state. They were married for many years

and had adult children together. Both of these caregivers sat next to their loved one throughout the interview.

Field Notes

Although I am presenting these findings first, they did not arise until after data collection was complete and themes and categories had begun to develop. I would like to give the reader some context for the interview settings and describe elements that add dimension as the interview themes are presented. The following categories of meaning developed from this inductive coding and analysis of field notes and are presented with the intention of illuminating the context of the interviews. Reflections on differences between participants and key informants are noted within the field note observations.

Field Notes: Diverse Aspects of Place

Participants selected a preferred venue for the interview, choosing either their homes or the oncology clinic. Spouses, children, friends, animals, TVs, nurses, and others moved in and out during these encounters. Seven of the participants preferred the home setting for interviews. The remainder chose to meet at treatment clinics, with the exception of one who chose to meet at my private office.

I was invited to kitchen tables, intimate living rooms, and once into a bedroom space in the middle of a very small efficiency home. All homes were unpretentious and sincere. They lacked grandeur and sterility, instead reflecting comfort, ease and warmth. Some dwellings seemed longstanding and well-established while others were physically and spatially modest, having created a sense of home out of a more practical, temporary place of shelter.

The first interview took place in a northern part of the state at a home situated inside the grounds of a busy car recycle center. A man sitting atop a large forklift at the entrance to the yard directed me through a maze of broken cars to the back – the edge of this lot where two trailers were perched on a rather steep cliff. Looking in one direction was a beautiful desert landscape and in another, mere feet away, lay a sea of mangled cars. Inside, the home was modest and well kept, packed with signs of life, a female dog with her new pups in a crate, and a young woman, the toddler's mother, preoccupied on the couch, watching television. The kitchen surfaces were cluttered with dishes and papers. The living room housed a couch, large television and right in the center, a treadmill.

In contrast to participant settings, key informants were interviewed in their place of employment. In one, I waited in a large, noisy and sterile multiprovider clinic waiting room for the physician to arrive, periodically knocking on the door to see if he had arrived; here there was no front office staff, greeters or gatekeepers. This primary care physician's office was a very small efficiency room shared with another physician, embedded within the space of a larger multipurpose clinic. There was enough room for two desks, a visitor chair and about 2 feet between. At one point the interview was briefly stopped as the office-mate entered to retrieve materials from her desk. Books and papers crowded this linoleum floored university-affiliated physicians' space.

The second interview took place in the office of a private practice oncologist. The waiting room, carpeted and painted with warm soft colors, offered magazines and educational materials arranged on low level tables. The background sound of a television could be heard. A clerk behind a glass window guided me through the many layers of the

clinic to his office. There were large, ornately framed family portraits and educational degrees proudly displayed on the walls. A large window with a mountainous view occupied one wall. The physician sat behind a 6-foot-long, dark wooden well-manicured desk while I sat in a comfortable chair across. There were no interruptions as we talked.

The final key informant interview was with a curandera. Her home/office was located adjacent to an empty lot not far off a busy street in an older neighborhood of the city's valley. An old adobe-style wall curved around an interior courtyard of the house. There were many beautiful herbs and flowers growing throughout. Her space was full of the life of a home, with every bit of space occupied– furniture, piles of magazines, books, artwork, flowers. As the interview drew to an end, she invited me into the treatment room at the back of the home. A hallway staged a sort of drugstore with wares and medicinal products that clients might purchase. A treatment table centered the therapy room with surrounding walls fully occupied by an eclectic array of items used during client treatments.

To summarize, the home spaces where interviews took place included extremely modest efficiency low income dwellings to simple yet tightly packed lower middle class homes. These homes seemed physically and geographically representative of low to lower middle class. The office spaces used to conduct interviews ranged from a large multimillion dollar state of the art cancer treatment facility to a small utilitarian shared office space and finally, one other private office setting, situated within a chemotherapy treatment room.

The three key informant interviews were discernibly different, yet they mirrored social expectations of public, private, and cultural places of healing – both Western and

traditional. In considering place of care, a stark difference was noted. Contrasts in social setting were evident between the neighborhood and home environment of the curandera versus the more established Western office-complex. These elements conjure questions around the impact contextual influence, social meaning, and values play on power relations and interaction between provider and patient. As Cummings and colleagues have argued, there is a mutual association between people and place, deserving of consideration in health and health-related research (Cummins, Curtis, Diez-Roux & Macintryre, 2007). Location of healthcare provision must be considered in the context of the position it places providers and displaces others; much in the same manner that how we dress and communicate both with body language and words influences perceptions.

Field Notes: Ways of Sharing and Evidence of Culture

Regardless of setting, there was a warm welcoming polite tenor to each participant interview. It was notable that on each occasion someone was poised and prepared to greet me, either the participant or a family member. The stage had been set, my place of sitting was clear. There was a sense that I could be in their home as long as needed, without an overt concern for time or urgency to move on in their day. Doors readily opened for this intimate exchange, as they knew I was there to hear about their experience of living with pain.

Bordas (2013) talks about *bienvenido*, a spirit of inclusivity, to approve, and to embrace as being central and core in Latino culture. The quality of genuine openness and hospitality that is *bienvenidos* resonated with my experiences. Here is a direct writing from the field notes as an exemplar:

> *He is so willing and seems engaged to talk about his journey as the tape reveals. He is articulate, emotional and animated all at once; wanting to recount the ways he had to literally show others the intensity of his pain in order for them to listen. He instantly becomes deeply moved and tearful in sharing the struggles with pain and communicating the severity to his providers. Even as it's time to end, he keeps talking and talking, all the way to the door, more story spills out. As I leave, he hugs me and wants to make sure that all of my questions have been answered. I have felt quite honored to be here today.*

The healthcare providers were also welcoming, yet there was a difference. They represented both private and academic settings, were collegial and professional but had a distinctively more straightforward and formal way of engaging. In contrast to the participant interviews the conversations stayed on task, rarely deviating and with an ever-present sense of time.

> *We met in his office – a small shared space. The desks and chairs in this two-person space would bump into each other when the chairs were scooted away from the desk. There was a small table and one little chair against an adjacent wall. He sat at his desk and I in the chair very near. He was clearly busy but tried to slow down and be present for the interview.*

The time with the traditional healer, a curandera, was collegial but in an entirely different, more personal way. I was graciously greeted at the door and guided past her kitchen area into a small living room space where we would sit. In spite of the lengthy interview, she took time to describe the function of some of her instruments of healing, guided me on the grounds, and with pride, vision and aspiration shared her future plans for the property. As with many of the participants, there was this liberality of time:

> *Neither of us seem to have noticed that 2 ½ hours has passed…she has graciously given me so much time just as she prepares to leave for a month-long apprenticeship with her mentor the very next day. She is very busy yet seems to have all the time in the world for me today.*

Interviews conducted in clinics had the familiarity of a healthcare setting – both for participants who were often well versed in the routine from their experiences during treatment, as well as me in my experience in practice. An awareness of time was more evident as the busyness of the clinic schedule was more apparent during these interviews that had been coordinated with preexisting appointments. In spite of the assurance of privacy during interviews, participants' ways of sharing seemed more re-active and formal in the "interview" context. Responses were more direct and concise. Some interviews in these settings occurred without the distraction of actively receiving treatment so there was no interruption. Others while private, and behind a closed door, did have interruptions as clinicians came to provide brief care. At these moments, the interview briefly paused. The cultural norms of a clinic setting can constrain the interview tenor, heightening a sense of the interviewer-interviewee formality and dominance of the clinical care needs over the interview.

These comparisons are made simply as a way to emphasize how *place* influences experience, manner of engaging, and likely what will be shared. There is an equalizing of power in the familiarity of one's home as well as a seemingly absence of concern for time, a way of being within the culture of Hispanic/Latinos and the influence hospitality and generosity of time.

Turning to another aspect of the interview context, and likely reflective of Hispanic/Latino culture, was the inclusion of family. To varying degrees and details, an awareness of connection to a larger group was evident even in the interviews that were conducted in clinics – family was either present or spoken of as part of the experience. If not physically present, others were included through pictures mounted on walls, placed

atop furnishings, and threaded into story and experience. Interviews happened all days of the week, usually during the daytime when one might assume others would be less visible. Only in one home was a spouse at work during the interview; otherwise people were in the midst.

This field note excerpt captured how intertwined the individual was with others. I have named this participant "Rosa."

> *She was outside the trailer when I arrived, well dressed and with a toddler hiding behind her leg. She greeted me and introduced the child as her great niece. Once inside the young woman on the couch takes the child and retreats without instructions, to a back room, seemingly to allow privacy for our interview. The interview pauses on several occasions as Rosa negotiates the needs or curiosities of others. For example, separately her adult son and husband check in; her daughter who lives in a trailer mere steps away calls to see how things are going; the dog needs to go outside, then later to be let back in the house. She seemed to be the hub of this busy household. The niece and child emerged from the back as they sense we are finishing and almost like clockwork the husband returned to open the front gate. Their home was rich with a sense of family and unspoken connection.*

While other people were part of my welcoming and in the midst during most of the interviews, they did not directly participate once the interview commenced. From my field notes of an earlier interview:

> *Her husband greeted me at the door. The house is immaculate. There has been a family gathering recently with balloons and adornments remaining. Pictures are notable throughout of her daughter and grandchildren. He led me to a kitchen table where she would sit across from me. He quietly receded as we began. It seemed he knew we were approaching the end of the interview and returned to sit beside her as we continued. It was clear that his role was to support her rather than participate directly.*

In contrast, there were two occasions that family members assumed they would be part of the interview. Both were eager to share their part of the journey. For example, Maria, in her 70s, had been birthed by a midwife in a very rural mountainous part of

northern New Mexico. She and her husband were high school sweethearts, and this attentive man sat by her side throughout the interview, contributing as much of the story as Maria did. There was a notable curiosity and protective manner about his engagement initially, reflected in this field note:

> *This is my first interview and the participant's husband greets me. He seems a little mistrusting and hesitant at first, but perhaps it is my own anxiety about this first interview. He directs me to a seat within feet of her bed; he sits in a chair directly across, next to her bed. He clearly is going to be part of this interview. Once we are underway, he is engaged and eager to participate. They seem an extension of each other – she looks to him when in need of more detail. At moments in recalling the first few months of her pain, tears welled in his eyes. He spoke with his whole body as he became more passionate, referring multiple times to the experience as a "nightmare." The stories seemed vivid, as if they happened yesterday, when in fact it had been four years ago. This experience seems to have been his as much as hers.*

In trying to situate the importance of family as I have witnessed, there was rarely a direct reference to family members sharing the suffering. Rather it seems that family may be more subtly woven in the fabric of the entirety of this cancer experience, including the witnessing and navigating of pain in loved ones. It was not uncommon as they spoke of their pain, that loved ones were somehow integrated into something that many consider uniquely individual. There was a sense of support and shared suffering among those who were present or spoken of during the interviews.

A final observation of culture is more difficult to describe. It really is more about how to listen to stories unfold. There was an elegance of storytelling that I have come to recognize living in the southwest. One of the primary participants, a curandero himself, healing others of their varying physical ailments, including pain, took many side roads to unveil his very personal story of pain. His responses to the interview questions were

thoughtfully and fully constructed, assuming the condition that the listener is to hold the space respectfully while the story unfolds.

A female participant did the same. She was soft spoken but thorough and articulate. I am reminded that she has a story to tell and there will not necessarily be a logical and linear connection between the comments. The story and its point will become clear if I wait, and listen. She is in command, is in control of the conversation, and there is purpose in the unfolding:

> *I sense that she sees her "job" as telling this story. There is a familiarity about the way she speaks that is part of her culture, a weaving of silence, slow unfolding of seemingly unrelated details, always making their way back to the topic. She will take her own route to telling the story.*

There is a difference between a nonculturally situated indirect process of explaining or answering a question, and this more culturally embedded style of responding. In the latter, there is not usually a need to redirect the speaker back to the original question; there is a need to recognize the approach and let it unfold. It seems critical to understand this subtle nuance as providers attempt to more completely understand experience, which informs assessment and management.

Field Notes: Financial Hardships

With very little prompting, some of these interviewees spoke of the financial limitations and adversity imposed by illness, including the rigors of schedules and travel. These tangential factors, not specifically related to pain, speak to the whole of the cancer care process which in all of these lives, included shades of pain. The transportation, housing, and social stressors that were very real parts of participants' lives, partially due to limited financial circumstance and resources, were exacerbated by their health

situations, all of which play a role in the whole experience of CRP, or any illness experience.

Maria lived in a humble one-room apartment with her husband in the treatment city. Leaving their home and family in northern New Mexico, they have called this small efficiency studio apartment "home" for nearly 2 years. After her diagnosis, they feared being stranded far away from her cancer care providers. This more temporary dwelling was less than a quarter mile from the cancer center, trading the comfort of home and community for the security of proximity. Everything about daily life is within a few steps – a bathroom, kitchenette, and sleeping area. Using religious artifacts and family pictures, Maria and her husband seemed to have done what they could to create a sense of home away from home.

The hardship of illness had forced others to move into family members' homes, lose or consolidate homes. For example, one participant lost his home due to the financial hardship illness had created and loss of employment. Edgar moved in with his longtime girlfriend/partner. He was forced to sell his home and consolidate possessions into one living space.

A final example of financial hardship was seen as I tried to schedule an interview with Erica. To be most efficient with her time, she elected to have the interview during a prescheduled visit to the clinic. There were competing demands of child care for her 2-year-old and train/bus schedule issues that interfered with setting up an interview. Finally after three tries, we did meet. Once we finally met, this 24-year-old mother spoke of how she was dependent on public transportation to get her to her treatments; the entire process one way took over an hour to navigate. Like Edgar, circumstance and limited

resources forced a change in living; she moved into her estranged mother's home with her son. Her husband had left them.

A Summary of How the Field Notes Align with the Study Aims

Assigning particular categories from the field notes is incompatible with participant meaning and hugely filtered through my own lens of perception. For that reason, the field notes remain a more "experience-near" summary of my understanding with visible links to the study aims (Geertz, 1983 as cited in Emerson, Fretz & Shaw, 2011, p.130).

The first aim (participant descriptions of the dimensions of the CRP experience) did not emerge overtly in individual or collective field note analysis but was present more implicitly. Participant experience surfaced through a desire to tell their story, a willingness to make space and time in their lives, and the ability to speak in the midst of the complexities of illness, its symptoms, and treatment.

Field notes aligning with the second aim (examining external factors and how context might intersect with the experience of CRP) included economical observations. The financial impact was reflected in hearing the burden of changing homes, losing a home, losing a job, and changing insurances, for example. Coordinating an interview time because of bus and/or train scheduling mishaps provided another glimpse into the social challenges some faced during illness. The field notes helped to situate the participant interviews and offered a context for better understanding their descriptions of their experiences with CRP. These notes illuminated aspects of navigating cancer with the overlay of pain.

Results: Themes and Categories

As a reminder and as was more fully described in Chapter III, the process of depiction and interpretation occurred in tandem and the final results of this iterative process are presented here (Vaismoradi, Turunen & Bondas, 2013). Analysis evolved systematically and reflexively, beginning by using an open coding approach, later evolving into separate units for closer examination. Atlas Ti with its architectural features allowed for organization of data into clusters of codes and subsequent themes and categories (Foley, 2002). Table 12 summarizes the early development of categories, which then evolved into the subsequent themes.

While each interview held unique elements and descriptive variations of how pain was experienced, including how participants coped and identified barriers, several common themes developed. For some, pain had been the catalyst to seek medical care at Field notes aligning with the second aim (examining external factors and how context might intersect with the experience of CRP) included economical observations. The financial impact was reflected in hearing the burden of changing homes, losing a home, losing a job, and changing insurances, for example. Coordinating an interview time because of bus and/or train scheduling mishaps provided another glimpse into the social challenges some faced during illness. The field notes helped to situate the participant interviews and offered a context for better understanding their descriptions of their experiences with CRP. These notes illuminated aspects of navigating cancer with the overlay of pain.

Categories were created from a composite of messages about very personal experiences of pain. What is described here were frequently recurring themes emerging

Table 12

Category Development from Data Analysis

Primary Interviews	Healthcare Providers
Pain Experience · Worst parts · Whole person · Meaning · Motivator to seek care · Interference · Consuming and fearful · Interference · Language of pain · Communication, trust and good care Coping · Spirituality, faith · Shielding others · Sharing sparingly · Personal strategies · Learned behavior from childhood, culture · Communication, learning to speak up · Attitude · Sources of support Barriers · Side effects · Misconceptions, perceptions, beliefs · Accountability and location of care · Access · Provider assessment and management Advice for Others (merged into existing categories) · Listen · Believe · Include family	· Communication · Accountability · Meaning · Looking through a cultural lens during encounters · Healthcare access · CAM approach to pain relief Family Caregivers · Experience – Perception of pain · Advocate Field Notes · Pain representing cancer - meaning · Interview interaction · Coping – faith, family, keeping busy · Barriers – economics of resources, time, energy, money

from comparative analysis of the accounts of participants, including concerns and experiences that surfaced in many of the interviews. Additionally, I have highlighted some singular yet important facets to consider relating to the experience of living with pain. I would not characterize these as "negative cases" but rather features not spoken of in all interviews, yet fitting within the study aims.

Table 13 summarizes the themes and their associated categories. Careful and

repeated systematic examination resulted in merging of categories, yielding a final collection of three themes and associated categories. Evolving categories were distinct yet interrelated such that the final assignment of categories into themes represents my interpretation and effort to relate them to the study aims. While the thematic categories may seem discreetly separate and independent, they were more intertwined as experienced and described by the participants.

Two major conceptual themes coalesced from the data analysis and synthesis that aligned with the first study aim, understanding the cancer experience as described by participants: *Pain Is More Than Physical* and *Ways People Cope.* I will describe each theme and associated category separately, presenting examples through individual interviews excerpts (Table 14).

Theme: Pain Is More Than Physical

The pain experience described by participants was largely situated into the first study aim of characterizing what living with pain was like for these individuals. While not all participants were having physical pain at the time of interviews, they all quickly recalled with great clarity what this had been like for them. Several related elements or categories link to how pain was exposed. *Pain Is More Than Physical* housed important aspects of pain which have been labeled (a) Meaning and (b) Whole Person Experience. I have separated what may appear as similar constructs, finding these elements deserved individualized description, yet they are linked to the larger understanding of how pain is portrayed. Other categories within this theme include the way people spoke of pain, the

Table 13

Thematic Categories Related to Understanding Cancer-related Pain

Pain Is More Than Physical	Ways People Cope	Hurdles and Hindrances
1. Meaning 1. Whole Person Experience 2. Language of Pain 3. Building Relationship and Trust	1. Personal Strategies 2. Culture – Internalized Expectations 3. Sources of Support: Faith and Family	1. Assessment, Accountability and Location of Care 2. Communication 3. Understanding of Medications and Side Effects 4. Being Treated with Respect

Table 14

Aim 1: Dimensions and Characteristics of the CRP Experience

Pain Is More Than Physical	Ways People Cope
1. Meaning 2. Whole Person Experience 3. Language of Pain 4. Building Relationship and Trust	1. Personal Strategies 2. Culture – Internalized Expectations 3. Sources of Support: Faith &Family

language, the importance of communication and the value of developing trust as foundational and reflective of what was considered good care. Each of these categories is summarized below.

Meaning

What pain embodied was complex and ever-present. Pain descriptions were multidimensional, often drifting into what might be considered separate constructs. I have described the major recurrent dimensions that became part of the pain conversation.

Many of the participants began explaining their experience of pain by returning to the time of diagnosis. Not all had pain as an initial symptom but several described how pain was a call to action and motivator to seek medical attention, which eventually led to a cancer diagnosis. Rosa's story described how she was trying to manage her pain on her own prior to a diagnosis, but then the pain became part of a larger array of concerns. She reflected on personal barriers that delayed seeking care:

> *I'm stubborn too. I just I would go through all that and still go to work and my husband…: Finally the bleeding got worse, and I would take baths to try to help the pain, like the cramps, and the bathtub filled up with blood, and there would be blood clots coming out about like this. It sort of looked like my liver or something, and then I finally… cause I started like throwing up and I was…had um…constipation really bad, and finally I decided to go to the doctor. I was stubborn, and I finally went because of the pain….*

And Erica, a young woman in her 20s told of waiting until the pain was so bad it required an ambulance to take her to the hospital:

> *[My husband at the time], he helps me out a lot. He would help me to get into the bathtub; he would call the ambulance for me if it [pain] got too bad. I was actually admitted three times in one month before they found out what was wrong with me.*

These are examples of the common experience of pain that precipitated seeking health care. A final example is Ramona, 63 years old, as she described her ongoing pain, which eventually led to a diagnosis of lymphoma:

> *The next day I started noticing that sciatic nerve got worse and then the second, it, it, I couldn't believe how much stronger that pain got, and so maybe I did hurt myself when I skipped over those two steps. So I said I better go get checked. The pain got so bad that I said I better go have it checked. Maybe I broke the main bone there or something. So I went, urgent care, and no… everything's fine. Then the weekend came and the pain just was worse. By Monday I couldn't even walk. It got so severe that I felt like I was walking with a butcher knife on my butt. I called my primary doctor and she-they told me, "Ok. Come on in." And she took an x-ray, and she couldn't see nothing wrong, and she gave me medication*

> *for the pain. And so that went on for about a week, and I kept calling the doctor's office and telling them that pain is not going away, it's not going away. And then she said, "Well, I think we need to do an MRI, there might be something deeper in there."*

It took 7 weeks to schedule that MRI. During this time she had become dependent on a walker to move, and was in excruciating pain until finally an MRI revealed lymphoma, rather than what was previously thought to be a work-related injury.

Her recollection primarily addressed the physicality of her pain but positioned pain as tethered to cancer in a way unlike other cancer-related symptoms seem to, it existed because of cancer, leading her to seek medical care.

Olivia, a middle-aged single woman demonstrated this interweaving of pain and cancer. She began by discussing how pain led to her diagnosis of melanoma, but shortly after, as we discussed ways she coped with her pain, cancer was part of the conversation once again. There was no untangling the two.

> *Mainly I think my pain was really in the tumor. I thought it was a cyst at first but it turned out to be cancer, tumor cancer.* Then later: *...that pain and cancer, I don't wish it on anybody. I've never had any other kind of illness. If it's anything like this, it's an awful, scary thing.*

Richard, in his early 60s said this:

> *I knew it was cancer before anybody else. I told every single doctor that I went to; I said "You got to help me with this pain." The pain is so excruciating and it just keeps getting worse and worse and I feel like it's growing. I can feel the inside of me growing and it's growing like this, it comes up my side, of course, lung, I didn't know I had cancer of the lung, and now in my hip was so bad, the grapefruit size tumor on my hip.*

Consistently during the interviews as we spoke about pain, without explanation or transition, cancer rather than the pain specifically quietly crept to the center of the discussion. I asked one participant to tell me more about how she dealt with her pain, and in the midst of the response she spoke about the anger she had at having cancer. Her

response, again, illustrated this phenomenon:

> *Just what I heard and in learning how to deal with the pain, of course, some anger, you know. It, when you find out that you have cancer or any kind of sickness, you could have a good attitude, but deep inside there's a little bit of anger. You think, "What did I do wrong?" Or you feel whiney, or "I'm going to hurt those ones that love me the most." You know? You tend to get very confused, especially when you're with the pain I had. I don't know how to describe it. It's like I said - there was days I didn't think I was gonna make it, it was so bad; I was gonna die, and I think that's when I would start to hallucinate. I thought, "I'm not gonna make it. I know I'm not gonna make it." And then I would wake up from whatever dream I was having, or nightmare, whatever, or hallucination, whatever it was, and I'd sit up in bed and say, "I'll do it. I know I could do it. I know I could do it." But yet that pain was there and I would say, "It's getting better, it's getting better." I would talk myself into it.*

Finally, another participant, Juan, a 54-year-old man with a recurrent brain tumor, spontaneously confirmed this finding. He clearly said, "*Yeah. Well, to me, it's been one and the same [cancer and pain]*."

Another participant described her pain and the meaning of her pain in a slightly different way. Landa, a woman with a history of breast cancer was receiving treatment for advanced ovarian cancer at the time of the interview. The notion of "managing" her pain held elements of nearing the end, death:

> *I guess now my problem with pain is with the anticipation of having to deal with what I found that was really really hard….;That kind of intense pain coming back. So I said to my doctor, um, I said, "What do I do if that comes back?" She said, "Well, we'll... we'll… we can manage that." I said, "How do you manage it?" … and she said, "Well, we'll put you in the hospital," and what they'll do is start giving you morphine. And I thought, "Well, … I don't want to be managed that way," but if it gets to that point and that's all they can do then I know that that's pretty much my final hurrah. You know, because I've been doing this for 13 years.*

Edgar, an avid and passionate home gardener, described in full detail the scope and breadth of his plantings. This year was different. His pain took away the ability to spend hours in the soil.

> *My garden has died. I can hardly look outside any longer. She* [his partner] *says it has died because I am no longer there. She can't keep it alive like I did. I just can't look out there and the pain is too much for me to try.*

When he spoke of the garden there was a sadness and grief. At a more superficial level his description began by way of reflecting how the worst part of pain was that he could no longer work in his garden – a precious part of his summer days. As he spoke it seemed that this garden just beyond the window where I sat, dry and dying, somehow was more about his journey than the plants.

Associating pain and death was not a central focus of the descriptions of all the participants, but it was present in many of the interviews. Some shared how speaking of pain to their family meant the end was near, that worsening pain was the alarm summoning progression of cancer and death, and pain was symbolizing the end of the journey.

There was notable variability and multiple layers to the participants' descriptions of the meaning and experiences of CRP. In addition to symbolizing their cancer and the possibility of death, pain was woven into the fabric of their whole day – the broader sphere of how pain showed up in the everydayness of life. Pain was described as a call to action, an alarm. It housed a sense of loss and grief; it represented the underlying disease; and for some, it was a warning of death.

Whole Person Experience

In the interviews, descriptions of pain extended far beyond a mere physical phenomenon. It enveloped parts of life that became shattered, thwarted or otherwise deeply affected. Stories were rich with description of the many parts of life that pain had

disrupted. Reporting of the totality of the pain included ways pain interfered with usual daily activities, becoming at times consuming. A final element to the meaning of pain was in descriptions of the worst part of living with CRP.

Pain interfered with sleep, treasured social and family activities, diminishing ability to engage with others, ability to focus, and role-responsibilities. People spoke of not eating well, or often of losing motivation, and of losing the energy or desire to engage with others. While at times sleep served as a way to cope, there were others for whom sleep was a barrier to engaging in usual activities. Interviews recounted stories of "retreating to bed" as a means to escape, isolate, and sleep – to go to a place where pain was less piercing.

Clarissa, a young woman with an osteosarcoma that resulted in a lower limb amputation, said this about sleep:

> *And it's so hard for me to sleep at night, especially with my leg just throbbing and the pain is so hard to explain, you know? Most of the time I'm up all night; it isn't as bad during the day so I sleep during the day. I hate that. I've been up all night so when the morning comes I'm in bed, sleeping, you know just to kind of avoid going through all that pain at night.*

The pain forced retreat to stillness, which robbed many of the time or ability to participate in favorite activities or daily living. Severe, activity-limiting pain led to physical deconditioning and depression for many. There were reports of feeling stuck in bed because it hurt too much to move which then led to feeling physically weak and emotionally exhausted. There was an associated sense of loss in all of these stories.

Erika, a young mother, spoke of her resolve to not let the pain get in her way. She felt forced to move and function in spite of pain. She recounted how being the only resource for her 2-year-old son did not allow interference.

> *With me, basically, I just suck it up. I have to because I don't have time to be sitting there in pain and trying to take something for it; I have a kid that I gotta take care of. I have things I have to do….I can't be stuck in bed all the time.*

Susana spoke about her limited capacity to endure what was at times, unrelenting pain as she shared a conversation with her 10-year-old son. With tears she recounted:

> *I told him, "My child, I'd live to be 150 if I could in good health, but in bad health, I can't, son. I can't do it. I hurt all the time." I says, "You don't want to see me like that, do you?" And he goes, "No, I don't like to see you hurting, mom, and crying." [I reply] "'cause I'll start crying when I'm in pain, I know, so you've got to think about that. You've got to think about, well, mommy really hurts today…."*

Juanita's pain began with the phone call that delivered the cancer diagnosis. She touchingly conveys pain as so much more than physical. Here the whole person experience was vivid:

> *So physical pain at that time I didn't have any, but psychological pain I did. When she told me I had cancer* [in my breast] *I was constantly [in] agony that you have in your heart. Like you open your eyes and nothing is like before. You cannot see that flower is beautiful. You don't see it. That pain in your heart covers everything. THAT* [is] *the hardest pain, pain that you need to deal with.*

For Jose, a middle-aged man with a brain tumor, there was a similar awareness of pain apart from the physical experience. While considering pain's re-emergence now that his cancer had returned, he talked of suffering as an element of pain:

> "*I have had the physical pain but it's the emotional pain that I suffer."*

Others similarly reflected this core, personal, perceptually-oriented nature of pain as a mind-burden: exhausting, emotional, fatiguing, and consuming.

> *…. I thought maybe I could cope with it but it makes me very, very moody. I get very moody. When I'm in pain I was sensitive to people's voices and stuff. I'd be like, oh my god, stop talking! You're too loud. I mean there's nobody with a bigger mouth than me and for me to say that…. "Just don't talk." That's how I know it's bad and I'm different….that was*

not me.

Aspects of pain were described as fear-evoking. The memory of pain for several conjured concern for the limits of their own resilience, should pain return. Worrying, casting doubt on their capacity to endure, predicting failure, and giving up were not uncommon.

> *I suppose I can use the word "worry" or have concern that I will have to deal with those things again. Don't know that, but I saw how my body was just in this place that I couldn't….separate myself from what was happening to me. I don't know if I could do it again.*

A more severe recounting of the consumption that pain created was from Olivia, the woman with melanoma. She said this about the pain:

> *That's something that I can't describe, that pain. In a sense you die, you're dead, and yes, you're alive, but you're in so much pain that you're dead.*

Edgar, living with a primary liver tumor for several years, was able to speak directly to the notion of what, for others, was more difficult to acknowledge, that if they had to live with the intensity of pain they'd experienced at some point along their illness, they might not be able to continue:

> *I'm sitting here. It's probably five or six* [out of ten - using a pain intensity scale], *and if I try and stand up, it goes to a ten, and if I had to live there I would kill myself. I wouldn't be able to handle that excruciating pain. If I can move, do things, I can calm down a little bit.*

In addition to pain's encumbrance on the necessities of life as well as the enriching aspects of life, participants described erosion to their sense of identity. A most memorable story came from Richard, a tall robust man in his mid-60s. He shared how he was physically compromised by the pain – such that the pain caused him to buckle and fall. He provided a heartfelt and expressive explanation of how pain had wounded his

sense of himself as a man. With tears in his eyes and a wavering voice, he said:

> *The pain, the pain took something from me; it took my strength. Losing my hair didn't do that to me. The hair took some superficial thing, but the PAIN took the body strength, and it made me feel weak and less than a man, and then it didn't get better.*

Edgar had this to say about how pain can overtake and occupy one's life:

> *….it's the day-to-day pain. Constant pain. What else? I mean, I asked myself that a thousand times. You're always in pain, and then it knocks the crap out of you. You think about it, and you know being in pain 24/7.*

And from another participant:

> *It took over my whole life. I stayed in bed for weeks at a time because I was in so much pain, and yeah, I didn't know what to do about it. You're a whole different person….I couldn't even see from one day to the next, much less a future.*

These reflections illustrate how participants connected their experiences of pain to aspects of the greater sphere of life and how it consumed their being. As part of the whole person experience, I asked participants to talk about the worst parts of having pain. Two ideas emerged – loss of independence and interruption in ways of relating to others. The issue of independence manifest as losing livelihood and the ability to care for self and continue in one's career. Young mothers and grandmothers described the inability to hold children and interact with them as they were used to doing. In many ways these worst parts were really another way of constructing how pain had interfered in their lives and likely reflected individual values and priorities.

One response to the worst part of having pain had not been voiced by others yet was quite directly tethered to this overarching connection between pain and cancer. Juanita, a woman in her late 40s, talked about what pain took from her – and it was not physical pain:

> *The worst, worst pain was when I found out that I have cancer. That blocked everything from me and I couldn't think. I couldn't do anything. I didn't know what my future is going to be and that thing was hurting me so bad that it didn't let me to eat. It didn't let me to sleep. Didn't let me to have hope. Nothing. I thought that in, in one second my life was totally dark, everything was dark. So that was my worst pain. Pain from surgery, that was nothing.*

An additional feature that evolved in the analysis was an examination of the language of pain. The following section captures the many ways participants spoke of pain, rarely encapsulated by a number.

Language of Pain

An important component of the experience of pain is found in the words participants used to describe their pain. Table 15 captures transcript excerpts of the precise ways that pain was described, presented within various domains of experience. The interview guide merely asked them to talk about the pain and what it had been like for them. There was no further direction for how or what to say about the pain. Reference to tools such as a 0-10 scale emerged only as a result of being given such language by providers. There were only a few participants who spoke of pain using objective rating scales such as numerical representation, and when they did, ratings never reached below five, midpoint on the 0-10 scale.

Alternatively, most of the interviews migrated to more personal and familiar language. Participants used more vivid descriptors. Accessing this language was natural and required little contemplation. The words used represented various domains of pain such as emotive, affective, and functional descriptors. Paying attention to language and word choice is an important feature for understanding the experience of how pain is portrayed.

Table 15

Language of Pain

Descriptive - *Numbness, tingling; pins and needles* - *Glass cutting me* - *A butcher knife in my butt* - *Stabbing* - *Burning* - *Shards of pain and pressure* - *Like my leg war trying to break itself* - *Like after a really bad yard fight* - *Never better than 5* - *Always an 8 out of 10*	Affective - *I wake up crying it hurts so bad* - *Excruciating* - *Like no other pain; nothing compares* - *Horrible* - *Suffering* - *Emotional* - *In my heart* - *A nightmare* - *Indescribable; could drive you crazy* - *Like fingers up under my skin - very scary*
Functional - *Your toes just curl up* - *I had to hold my breast because of the pain* - *Like a whole body workout of* - *6 hours & then I couldn't move the rest of the day* - *I went to sleep to get away from it*	Location - *Joints* - *Kidneys* - *Liver* - *I would have pain in my leg, but it was cut off!*

Building Relationship and Trust

The final category that emerged as participants described CRP focused on the interactions with the health care team. There were both positive and negative interactions that directly related to their level of comfort talking about pain, with being believed and feeling heard. When participants perceived a strong trusting connection with their providers, there was an increased willingness to follow guidance for their pain management practices. For example, both nurses and a non-nurse patient navigator seemed to serve as conduits for several participants. Trust and "connection" was established such that they spoke freely about their pain. It seemed that these providers were able to successfully provide coaching around misconceptions and concerns related

to pain management and medications. Olivia's message speaks to the foundational need for trust and relationship:

> *I know she's not a doctor or a nurse, but I just got a lot of confidence in her and a lot of trust. She became a very special person to me; that's important to trust somebody because this is your life that you're talking about, this is your pain you are talking about. She would sit there and feel like you could sit there and talk to them and they're not going to judge you for what you say or who you are or what you do or because you are in pain…it's really important. When we would talk, I thought, "Well it's okay now." I wasn't afraid to take my medication. We have a connection.* [And also with] *Miss Susanne, my nurse, I thank her for her encouragement in letting me know how important it was for me to take my meds for those, that pain to go away. I was just so scared of the meds.*

Clarissa, with an osteosarcoma that required a lower limb amputation, resulting in phantom pain, contrasted encounters she had with her medical provider and a patient navigator. She spoke of how the medical provider had not listened nor believed her situation. In comparison, she reflected on what the navigator did that developed trust and advocated for her:

> *So then she came in and said, "You know what? I'm gonna sit with you." And she did. And she saw the way they [medical providers] talked to me, and she just kind of put her foot down and said, "Hey look. You can't talk to her like this." She felt like I needed to see someone that would sit there and talk to me. She got me to meet with another doctor and he was the one that sat down with me and he told me what was going on and listened to me about my pain. I'm glad for him because he listens to me and he talks to me, you know?*

In her final reflection on the overall care she received from providers, she echoed the sentiment of others, sitting and listening really matter; feeling heard and believed were central in the relationship and experience of pain care.

> *It makes you feel good when you have that support and you have the doctors telling you "Ok, well, you know." But it's, it makes you feel bad, too, when you know that these doctors have been <u>your</u> doctors for the longest time and that they're not treating you the same. You know? And what upsets me is I see some people that walk around or they're doing*

> *their normal activities and they are getting so much* [pain] *medication and I can't even get no pain medication and I ain't got a leg. You know?*

Finally, there was mention of two important elements when communicating with people – medical literacy and preferred language. One participant pointed out how comforting and essential good communication with his provider was; to not speak in medical 'mumbo jumbo'; feeling he could freely ask questions and could understand the answers. In another case, Juanita, who was quite proficient in English, needed the comfort of her native language to discuss details of her diagnosis. She was born and raised in South America but had lived in the United States for the past 11 years. She recalled being able to speak with a Spanish-speaking health worker soon after she had received her diagnosis by another, over the phone in English.

> *I feel like I was talking to somebody that I know, known forever. She spoke my language! And then I met a Chilean doctor. She spoke Spanish. It was so amazing! My primary doctor that I was seeing, I didn't call him. He's a very nice guy but once again, I don't trust. I needed somebody that spoke my language. I need to hear this in my language.*

Closing Thoughts on Pain Is More Than Physical

Rather than simply describing physical attributes of pain, participants often discussed the meaning of pain, and how this experience of pain was connected with and affected many parts of their lives. Talking about pain often became talking about their cancer. There were also vivid aspects of how pain spilled out from the physical, taking over the way they interacted, functioned, and how it interfered with the whole person.

I was not expecting to hear such a variety of words characterizing pain. It's important to note that I never asked them to describe their pain, rather this was their way

of helping me to understand more fully and often vividly, what that was like. Again, an important awareness is how infrequently the language included linear numeric scales.

A final feature of how pain was described included the central role of how the cancer patients/study participants communicated with providers and how providers communicated with them, how trust was built, and how these elements either lent themselves to being labeled good or bad care. The interviews focused mostly on ways that good communication and trusting relationships were central to the fabric of good care.

The next theme summarizes yet a different aspect of pain – how people described managing their pain. Seen here were strategies for day-to-day self-management; key features they felt were important to successfully navigate the pain, including support and faith; and where upbringing and early scripting and expectations of how to behave played a role.

Theme: Ways People Cope

Prompting questions in the interview guide helped start a conversation related to coping. For example, I asked, "Can you talk about ways you deal with your pain?" and "What ways do you try to help relieve the pain?" In addition, I asked about how culture, upbringing, family, or spiritual beliefs may influence pain. All of these questions led to many strategies and influences for navigating the everyday reality of living with pain, including in-the-moment strategies, some of which were learned as children and reflective of culture and upbringing. What coalesced from these questions seemed to represent what people did to try to manage their pain in ways that were and manageable.

Other aspects of what participants did to cope, included support from family, community, faith, and healthcare providers (Table 16). A final category of what people did to cope was to shield others in order to minimize the burden upon loved ones.

Personal Strategies

I heard the most about personal strategies used to help ease pain. Retreat into sleep as well as sheer distraction, were expressed:

> *If I felt it hurt too much because it would make me so tired, the pain you know and I would just get so tired. I started feeling depressed and so I would stay in bed. Sometimes I would just sleep for days. But now [without pain] I haven't been, I feel really good.*

Another form of distraction was to get lost in something else, work or other form of escape:

> *I place myself in a landscape at the time, my girlfriend's yard, moving rocks and just distract myself. I did the [radiation] therapy, and now I go down south and dig up ocotillos* [large cactus-like spiny plants] *to help distract from the pain.*

Richard, a self-claimed healer himself, found that when he was working with his clients, he was able to step out of his own pain:

I do a lot of muscle work with clients. I'm in pain but when I walk into that room, that's my escape. All of the sudden, I'm good…I'm happy,

Table 16

Ways People Cope

Categories
1. Personal Strategies
2. Culture : Internalized Expectations
3. Sources of Support: Faith, Family & Community

> *because I love my work. I'm happy and I feel good, I don't hurt in there and I'm not tired. I can focus on something else.*

Effort to keep from slipping into a depressed state came through in many interviews. Maintaining routines, using distraction, and minding one's attitude were all ways to avoid depression. Many spoke of "keeping a strong mind," "being upbeat," and employing a positive approach.

> *Thinking, trying to think better things, you know…I felt myself trying to go into depression when I would be in bed with pain. I kick the covers off and go do anything, make dinner, clean, whatever. I didn't want to be depressed and you have to fight it, to act better, to be able to handle it [pain].*

When inquiring about how culture and upbringing may have influenced how they cope with pain, the major elements were being strong and stoic. Some spoke of childhood injuries or even rites of passage where no particular indulging or attention was given to injuries or physically difficult situations. Being silent was encouraged while tears or other expression of pain were discouraged.

> *…if I can manage to just ignore that I'll be fine, because I know I'm fine. And it's nothing to freak out about. Growing up my mom didn't freak out even when a nail went through my foot.*

The concept of *macho* or *machismo* was volunteered by several participants and by both caregivers that participated in the interviews. Two examples capture this feature:

> FEMALE CAREGIVER*: I think in our culture, it's a cultural thing too. We are very silent sufferers for whatever crazy reason we…*
> MALE: *For whatever reason.*
> INTERVIEWER*: Who's "we"?*
> FEMALE CAREGIVER: *Women, I'm talking about Hispanic women.*
> MALE: *Hispanics in general too. I would say in men too.*

In the context of discussing macho culture, a male participant agreed that it came from his upbringing:

> *My dad never moaned. We didn't know when my dad was having heart trouble until he died of heart trouble, heart attack. That is how I learned to deal with pain.*

This idea of being brave was also recognized by a female participant. She spoke clearly about the general culture not being focused on pain but rather healing:

> *No….. my family didn't talk about pain. Nothing. Nobody. Even my friend. My friend is also from my country. So all of us in the Hispanic culture, nobody talked about pain. Everybody was focusing more on, "You're going to get better. Don't worry. Just go through and be brave. That's it."*

Also situated as part of culture was the intentionality of shielding loved ones from the intensity of the pain. Minimizing or hiding the pain was done in an effort to protect loved ones from added suffering and frustration. There was an awareness of the worry imposed on those that cared for them. The following examples from different caregivers offer examples:

> *I don't tell her [mom] a lot of the times I'm in pain. I just go to my room and I'll lie down for a little.*
> *I had a lot of open doors. But yet, I closed myself up in a lot of different ways. I could talk but if I didn't have to, I wouldn't.*
> *I don't like to tell people about it. The only person was really my mom. Even my husband seemed like he didn't understand or would get frustrated, wanting to fix everything.*

A final component of coping that seemed to be part of culture was the use of heat and cold to help alleviate pain. This strategy seemed most fitting with expressions of internalized scripting from upbringing. Using temperature in some way to alleviate pain was a suggestion that typically came from someone in the family, or from themselves, not from a healthcare provider. It seemed usually either hot or cold compresses, not both, or simply getting into a hot bath to reduce the pain.

Faith and Support

Two other characteristics of coping were commonly represented – faith and the importance of family and support. Many participants said that God was first, the healthcare team came next. Healing was sometimes seen as in the hands of God. They reflected on the importance of prayer in how they dealt with the pain.

They also spoke of the importance of a partner in making decisions; decisions about treatment as well as how to manage their pain. Partners included sisters, parents, children, or spouses. These were the people who advocated in many cases, speaking up on their behalf, holding witness through difficult times, and sharing in the suffering. Two participants had partners that stayed in the interviews. It was the very act of assuming they were part of the interview that spoke to the shared, collective "experience."

Juanita described incongruence in terms of how family offers support, comparing her country of origin to the Western culture. While her perspective was not as strongly voiced by others, there were common elements.

> *In the place where I come, they do everything to be with you. My sister got her VISA to be with me. She left everything. She sold everything in her apartment and she came here to be with me in my last surgery and she's still here. She's going to go back, but she's still coping with me. So, when that thing happened, when there is that type of pain, my psychological pain that people are suffering, we don't care about material things or anything. We need to be with those people. So, the pain goes to everybody. It's not only one person, because even my brothers, that they are very macho guys call me crying and "We want to see you," and "What we are going to do" and all of that. So it's like group. It's not just an individual.*

Again in English, her second language, she made a notable observation of the strict adherence that Western healthcare has on speaking to an individual rather than a family.

> *They go specific to you....my daughter and my husband were making a joke saying "Oh the doctor came to talk to ME. The doctor came to talk to ME." If you see a group of people there waiting for you to get better, what's the problem to talk in front of everybody? So, pain goes in a group in my culture. It's pain for everybody. It's pain for my mom, my sisters, everybody and I really would have want them to be part of that.*

Juanita more explicitly than others has illustrated the importance of a collective experience, unlike the individualist approach that usually frames care and communication in the United States.

In summary, the way people coped was a major theme of the first research aim of understanding cancer-related pain. Pain in these descriptions was not only a personal individual experience, it was also social, drawing on support from others as well as shielding loved ones from the pain. How pain was perceived seemed certain to influence coping, connecting the theme of *Pain Is More Than Physical* to *Ways People Cope*. For example family and faith helped navigate fear behind the meaning of pain – its connection to the life threatening illness. There was a more discreet separation of cancer from pain when talking about coping. There was less mystery as to whether we were talking about cancer or we were talking about coping with pain.

Themes and categories presented thus far have primarily aligned with Research Aim 1 - understanding and characterizing the CRP experience. The final theme, *Hurdles and Hindrances* primarily represents barriers, which are situated more fittingly with Research Aim 2 - exploring aspects of social, power, and structural influences of the experience of CRP.

Theme: Hurdles and Hindrances

This theme developed from participants' descriptions of their experiences in seeking medical treatment and relief from their pain. What seemed a common thread throughout these categories was the issue of making their way to relief and encountering barriers. Hurdles are meant to represent an obstacle or difficulty that impedes pain relief while a hindrance symbolizes greater burden and may limit progress or halt it altogether. The severity of such conditions varied, but there were no negative case examples of the absence of obstacles or difficulties when it came to the experience of CRP. In other words, no one had a stellar experience of having their pain managed without challenges. Four categories as part of this theme included both system and personal barriers (Table 17).

Pain Assessment, Treatment Accountability, and Location of Care

Obstacles and interferences to pain care were related to healthcare providers' lack of accountability for complete assessment of pain or optimizing treatment and evaluation. Fundamental misconceptions persisted. Providers commonly failed to ask about pain;

Table 17

Hurdles and Hindrances

1. Pain Assessment, Treatment Accountability and Location of Care
2. Communication
3. Understanding of Medications and Side Effects
4. Being Treated with Respect

more often they responded to cancer-related pain concerns when the individual raised the topic.

> *I'd be sitting there thinking, how am I going to bring this [pain] up? How am I going to tell them? They would never ask me. They never told me how to take the [pain] medicine. I just had to take it when I thought I should which made me nervous. I know a lot of people that the doctors just give them pain pills but it wasn't like that for me. They didn't ask and it was hard to get the medicine – and I have cancer!*

Clarissa, the young woman with intermittent phantom limb pain had much to say about the hurdles she encountered with providers related to treating her pain. The interview text here exemplifies the challenges of being believed and where she had to go to receive some degree of care:

> *When I got out of the hospital for the amputation, they sent me home with 5 mg Oxycodone pills, and it didn't help me. And so I had to go to the ER, but they didn't understand. I'm like, "You just took my leg; how am I not supposed to have pain?" It's not that I'm just trying to complain or be difficult. I'm just saying, "Hey! I'm in pain!" Like I tell them, "Look at me. I ain't got no leg."*
> *About the only time I would get something for pain was when I went to the ER. The surgeon especially didn't want to give me anything – he never asked me about my pain.*

Not everyone felt that providers were not asking or believing them about the pain but there were an unfortunate and disturbing number of times that this was the case. Determining the underlying source of cancer pain can be difficult and is not always evident, making management more challenging. Ironically, all of the study participants had a quickly identifiable source of pain, as it was associated with the cancer or treatment. For this reason it is even more distressing to hear of the challenges encountered in having providers consistently assess and manage their CRP.

A different aspect of accountability related to pain care arose during the time prior to diagnosis. Prior to diagnosing that the large retroperitoneal mass

was lymphoma, Ramona recalled limited effort by her team of healthcare providers to manage her physical suffering and pain. It took 7 weeks to approve an MRI and in the meantime she had become bedbound due to debilitating pain and dependent on a walker to merely move about her house. The pain had become so unbearable that she was admitted to the hospital and intravenous analgesics started.

A final example of accountability comes from Richard. He eventually was diagnosed with a metastatic lung cancer but in the meantime, much like Ramona, pain management was lacking such that as you will see, he had reached desperation:

> *I knew I had cancer before anyone else. I told every single doctor that I went to, I said, you got to help me with this pain. It is so excruciating, and it keeps getting worse and worse. I can feel it inside of me growing. I told my primary care doctor, please give me something to get this pain down. She said I had oxycodone, but I told her over and over it wasn't working for a long time now. They would tell me, they would say, "You exaggerate so much." I could even tell them how many times I fell at home asking please for them to do something [primary care]. She wouldn't give me oxycodone because they've got regulations they have to follow about how often they give it or something like that. I was having a horrible time. So then before the next time I had an appointment, I didn't do my stretches or take any pills - I was crumpled up when I went to her office. Then I told her the whole story again. This time she said, "Okay, let's go get an X-ray." As I got up she could see how horribly I was walking AND using a cane and said, "I've never seen you like this," and suddenly she got worried and things started to change. I told her I was almost ready to stab my "ass" and do something that would force someone to take an x-ray where I was having pain – so someone would look and see there <u>was</u> something very wrong and start giving me medicine.*

While accountability issues cut across care settings, a unique subset of challenge came from primary care and other nononcology specialists as well as rural versus urban locations of care. Two exemplars presented here represent the discourse of pain

encountered with primary providers, prior to the patient's diagnosis. Participants found it challenging to convey their need for pain care and felt there was resistance when dealing with their local community providers. Often they needed specialty care instead. There was a perceived gap when care was transitioned from cancer specialists to the primary providers. One notable exception to this occurred in which superior pain care came not from an oncologist but from a palliative care provider. The lack of responsibility or accountability was seen between disciplines as well. For example, some felt nurses didn't follow through with conveying the patient's needs to the provider with prescriptive authority. A constellation of provider types were identified as being less than assertive in taking a leadership role in managing their CRP relief. The following collective from one participant illustrates the accountability issue:

> *Well, when I was done with radiation and I still had the pain in my ureter, I would tell them, and they would just say, "Well, you need to talk to your other doctor 'cause we're just here for the checkups, you know." We don't really see you for that. They wouldn't give it to me either. I needed to go to my regular doctor, and then they don't really understand either! Some of the nurses over there would say, "Oh well, let me ask the doctor." And then they would never come back to me, and I didn't feel I could ask if they did talk to the doctor. I felt like I would be judged. Like if maybe they would think I was a drug addict or I'm hooked now or whatever. I didn't LIKE to take them [pills].*

Somewhat related to nonspecialist care, Edgar with a large primary liver tumor was the only participant in the study who came close to making an association between ethnicity and pain care. He had examples of positive interactions with providers listening to him, but there were other participants for whom that was not the case.

> *For some reason here in New Mexico they really stereotype male Hispanics. I just happen to be Hispanic and I feel it. I was in rehabilitation after being really sick from the treatment, and for whatever reason this pain specialist was trying to get me off morphine. I don't even like taking it so that made me feel even worse about it. "You shouldn't be*

on this you know." At that time I did feel like being Hispanic was why he was saying that.

Communication

Accountability and the provider's responsibility to perform a complete assessment are closely connected to communication. Many of the barriers described by the participants were indeed related to communication gaps as well as to power differentials between patients and their providers. Communication was inconsistent between patients and providers, happening in a variety of settings and types of providers.

Half the time you don't even know what they are saying – they use words you don't understand but some people helped me understand. The navigator where I get treatment, she would explain it to me. Not the nurses or doctors.

On a more fundamental level, details of managing medications were scant. Several spoke of not being asked about their pain (assessment) or not being told how to take the medication, how to prevent pain, or how to manage side effects. Many said it was something they learned as they went along, a sort of trial and error approach. When I reflected back to one person during the interview that it seemed she had really learned how to manage the pain on her own (in terms of the medicine), she replied:

No one ever really told me how to stay on top of the pain. I was afraid and didn't like to take pain medicine in the first place. So it would get out of hand. They never talked to me about that. Eventually I just figured I had to take it when I needed it. I guess you have to find the right doctor. I did find one and she understood. And the nurses when they changed my tube, I didn't feel a thing. Sometimes it was really good.

Juanita, after her mastectomy, had a similar experience with receiving limited education about her pain management:

I was walking bent over in pain and the nurse just looked at me and said, "Just push it when you are in pain." But nobody asked me, "Are you in

> *pain? Don't worry. This will help you." I never really understood how to use it.*

Many participants raised the concern about being labeled as a drug seeker or as a complainer. Those that did speak up recognized the risks – the most significant of which was the risk of compromised care. The consequence of expressing frustration or struggles with the adequacy of pain care led to judgment and withholding of analgesics for one:

> *…They won't listen to me, you know, when I try to tell them how or what kind of pain I'm having. It's – instead of saying, How can I help you?" they're saying, "Well, it's in your head and why are you letting it get to your head?" I said, "Look, it's not in my head. It's real, you know." But they don't want to listen to what I have to say. And ever since I got diagnosed, I've been honest with them. I told them I smoked pot since it was the only thing that helps get me to where I'm feeling comfortable. …He tells me "Well, I'm not giving you pain medication if you're on pot."*

For others there was a sense of defeat – that they had communicated their pain so many times, that they grew weary and stopped trying.

Gaps in communication extended beyond the logistics of pain assessment and management, taking a solid seat with an underlying lack of prioritization of pain care and a diminished sense of meaning and importance. Story after story touched on this fundamental issue – needing to learn to speak up on their own behalf or a caregiver advocating, simply not being asked or believed, and finding various providers not taking accountability for the pain care. There was certainly episodic case examples of acceptable pain care, of compassionate physicians and nurses engaged in providing good pain care. What might constitute "good care" or a positive experience with providers contained basic elements of human connection and respect. There was a sense of seeing

the individual in their fullness. Unfortunately not a single story was exempt from some degree of resistance and communication hurdle along the way.

Understanding of Medications and Side Effects

Another longstanding issue considered a barrier to pain care was described by the participants – understanding of medications. Incongruences here could arguably align with the first study aim, relating to participant experiences and beliefs, but it was brought up in the interviews within the context of being an obstacle to pain relief.

Participants raised concerns with addiction, and for one in particular with a past history of drug use this was a major concern. This concern with becoming addicted again was an obstacle to taking her medications. Not only from her but others, there was a concern of being labeled an addict or abuser by providers. No examples of providers overtly labeling patients in this manner were provided, yet it was an ever-present concern voiced by participants.

Some participants also expressed concern with reaching a threshold of effect if they were too liberal with dosing the pain medications, so they would wait until they couldn't stand the pain any longer before taking the medicine. Finally, an association with death was made with taking morphine. Table 18 summarizes these concerns with exemplars from the interviews.

Table 18 also highlights a list of side effects that posed concern and interfered with taking analgesics. For example, the concern with becoming sleepy spoke to how the pain medication interfered with activities of daily living and social interactions. There was often a hesitation with taking medication, preferring the alternative, in order to carry

Table 18

Understanding of Medications and Side Effects

Understanding of Medications	Interview Text Exemplar
1. Concern with becoming a 'user', 'addict' or 'hooked'	•*Here I am worried about being addicted when I have cancer. I mean it doesn't make sense. But all my family members have had an addiction.* •*I was on drugs for a couple of years in the past and was really scared of that.*
2. Concern with provider judgment	•*I felt like I would be judged. If maybe they think that I'm a drug addict now or I'm hooked on them….I didn't like to take them [medication] because I couldn't sleep.*
3. Concern with efficacy threshold	•*I wanted to wait until the pain got really bad before taking it.*
4. Morphine – a signal of end of life	•*I think if I was close to it being the end – I know that sounds morbid but…I think that the morphine would come into plan at that point. I used to give it to my dad before he died*
Side Effects	
1. Sleepiness, interference with socialization or engaging with others	•*It knocks me out for the day and I can't do anything. I can't take care of my son.* •*I couldn't drive and I didn't like that – can't drive "under the influence"* •*I feel like I might be too sleepy or something so I don't take much but I'm in pain all the time*
2. Feeling out of control	• *I'm afraid of the mediation, the heavy stuff you know. I don't know why.* •*I couldn't do my puzzles. I was fuzzy and dizzy and not myself*

on with required or desired activities such as child care, gardening, or leaving the house to socialize or engage in necessary life tasks.

Being Treated with Respect

As interviews were concluding, in an attempt to capture features that might not otherwise be drawn out, I routinely asked participants for specific advice they would give to others in their same situation, experiencing CRP and what advice they would offer to providers. In addition I asked if there was something that I *didn't* ask that I should have asked. The premise for these questions was that concluding the interview by using general reflective questions might encourage additional insight and memory.

There was a far greater inclination for participants to offer feedback to providers, possibly because I represented a provider position or maybe they were simply eager to openly and safely illuminate unmet needs, concerns, and challenges. What evolved largely focused on improved communication, not only from a human connection perspective but also in terms of language accessibility and sensitivity to medical literacy. One type of advice to providers that came through many times was that they need to remember that they are talking and dealing with real people. Treating the patient as a whole person or being treated with human kindness was strongly encouraged.

Rosa, whose cancer was controlled and pain recently waning, responded with an embodiment of the many layers and effect of pain on all of one's life:

> *I think they need to get a little more personal with you. They act like they have so many patients, and they don't seem to care. They need to care a little bit more…not because you have cancer, but because you're a person and have feelings. Not just "Well, how are you feeling today?" I'm talking about how YOU are feeling…how is YOUR pain making you FEEL? Is it making you down? Are you feeling depressed? They never ever ask me that. I had a lot of pain and they didn't think it was pain. They need to have a little more feelings.*

The sentiment was also raised by a spouse:

> *Just listening to you….listening to you. That helped me. I haven't had to go to anybody because they've been filling my needs and they know how to listen [referring to clinic staff]. That they just sit down with you looking you in the eyes and just 10-15 minutes they spend with you**,** OH TIME WELL SPENT!*

To simply sit down and listen, to advocate on their behalf – that was a message to nurses as well:

> *I don't know, they just need to take the time to sit down and talk to their patients, you know. Get to know more about the patients, at least try to bring them up and give them some kind of good news.*
> *In the hospital, nurses need to go out of their way a little bit. They didn't go out of their comfort zone. They had their protocols and they won't call*

> *the doctor even when that protocol isn't working. One nurse did. That nurse got my medicine changed. He really stuck out and I will remember him.*

A final aspect of *Being Treated with Respect* included not having to essentially prove one's pain by grand expression, but rather that they could simply be believed. Susana, a woman in her early 50s, married, with grown children and one small child still at home, raised something not openly discussed by many others, that there might be something different about how she as a Hispanic woman would express her pain. While receiving chemotherapy and with an adult daughter at her side, she had this to say as our interview drew to a close:

> *Believe me when I'm in pain. Don't second-guess and don't question your patients in our situation. It's not the time or the place. And you don't have to be crying and screaming like some people, to be in pain. That might be something about Hispanics, men and women – silent sufferers for whatever crazy reason.*

Lastly, an isolated response came from one participant, in response to the inquiry about things I should have asked but had not. Juanita, from Chile, recognized I had not asked about her family. Her interview talked a lot about family and their importance in her life. Juanita was the one participant more closely tied to her home country, only having resided in the US for 11 years. She said quietly that maybe I should ask also about the pain that her family was feeling.

> *Maybe the pain that my family was feeling…..my daughter was feeling. When I heard her cry, you know, her bedroom in the evening sometime, because of me. Maybe that pain was also in the house. It's like, it's like when you have cancer, it's like everybody has cancer. Is when you are an alcoholic person, everybody's like has been drinking in the house, because that thing that goes around.*

Her recollections focus on the critical importance of experience that transcends the individual and highlights the centrality of loved ones in the framework of illness and

healing.

In summary, barriers to pain care and relief were a mixture of provider-focused external factors, personal internal beliefs, and medication side effects that challenged the management of pain. Patterns that coalesced into this third theme labeled *Hurdles and Hindrances* reflect aspects of provider-level barriers, and the influence of power and position on the experience of pain. Most directly, their described experiences with health care providers reflected misconceptions and negative attitudes, lack of accountability to assess and manage pain, power differentials, and ineffective communication styles which did not leave them feeling valued as a person.

Additional Data Sources

Key Informant and Family Caregiver Interviews

There were three key informants, a university-based family practice and palliative care physician, a community-based oncologist and a community-based curandera. An interview guide framed the key informant interviews (Table 19).

Three additional and unplanned sources of human data came by way of partners and a sibling that remained present during the interview. These individuals assumed they were part of the interview and without question stayed present and actively engaged during the interview. Questions and conversations that were part of the primary participant interviews were open to them for response as there was not a formal interview guide for the spontaneous family caregivers that participated in the interviews. Their comments were coded separately as part of the analysis and are presented here as they align with developing themes.

Table 19

Key Informant Guide

What Research Wants to Know	Method	Sample Questions
Participants personal experience of life in the setting of living with cancer-related pain	Interview Document Review	Many people with cancer experience pain. It is important in providing nursing care to people experiencing pain to understand as much as is possible, what that experience is for the individual. I want to learn from your experience and perception of caring for or assisting persons with cancer-related pain. 1. Can you start with how you come to interact or work with persons that might be experiencing cancer-related pain? 2. From your experience how might you portray the way Hispanic/Latinos talk about or share the story/experience of their pain? 3. Do you know of folkways that people care for their pain? Who might help them in this type of care? 4. Are there any other general things you would like to share about the topic of cancer-related pain among Hispanic/Latinos that you see? 5. Do you have thoughts about others that might have good insight on this topic?
The barriers, obstacles and other factors in the environment that influence living with cancer-related pain.	Interviews Document Review	1. Do you see aspects of the person's pain experience that might be outside of their physical experience that interfere or affect that experience? (if needed, could guide with items here): a) Work b) Family roles; responsibilities c) Financial d) Healthcare system/ language/access/etc. 2. How do other think the community responds or understands cancer-related pain? a) Family and friends b) Others in the Hispanic/Latino community c) Others outside the Hispanic/Latino community 3. Can you talk about ways the healthcare system influences their experience of pain? 4. Is there anything about their culture that might influence the experience of pain? 5. Are there other general areas around barriers or obstacles in the environment that might influence their experience of pain?

Key Informants - Providers

It is important to be clear that these key informants are quite different in terms of their specialty, each interfacing in a unique way with Hispanic/Latinos experiencing CRP. The following section summarizes the providers' contributions and describes alignment that developed from these interviews with the primary themes. I begin with the curandera who provided insight and perspective that resonated with four themes or related categories.

For this presentation I have named the curandera Louisa. She spoke of the relationship of heat to pain and offered examples of how traditional healers would use heat to empower individuals toward healing Personal strategies might include using a tea with herbs that provide cooling, applying heat or cold to an area of pain, "cupping" – a treatment that applies fire over a painful body part, and a technique called "bleeding" – a treatment not seen much in the US at this point in time. The latter technique allows blood to open congested energy. Other interventions that she teaches include mud bathing or foot soaking with particular herbs to cool and remove toxins. The primary interviews with her reflected the use of heat and cold as her personal strategies, but she was less articulate about where she learned them. Louisa very much saw this practice as rooted in culture. It is noteworthy that the medical providers also addressed a presence of heat and cold references among Hispanic patients.

> *Actually, it's interesting because there is a lot of temperature, there's a lot of temperature-related adjectives used in describing pain. Yea, yea, like hot, burning….freezing cold. In talking about neuropathic pain a patient said: "My body gets hot all over when I feel this backache."*

A second cultural observation was made around the notion of silent suffering, as mentioned in an earlier interview. Louisa spoke at length about how children who have

injured themselves or are otherwise hurting, receive no special attention as long as it is not life-threatening. This translates into adulthood as machismo. For example:

> *And I think that as Hispanics generally, it's almost like their penance in the pain, as far as pain. It's real hard for Hispanics, especially Hispanic men to say that they're hurting. They don't want others to know or to see them in pain. So when you start dealing with people with pain management you have the ideology of pain, like are you weak to say that you have pain? If you've suffered so much that you have had pain. If somebody else has it worse, like why would you worry somebody to say you're hurting?*

Related to enduring pain was a behavior of withholding treatment until the pain became excruciating. Men see it as pride and women as a way to protect others, to shield them from worry. With this awareness, Louisa felt providers could use education about preventing pain, explaining that medication is not a "cop out." These ways of remaining silent and stoic supported the cultural expectations that participants also reported, as part of the theme *Ways People Cope*.

Conversation about culture was threaded through interviews with the medical providers, just quite differently. Because of their backgrounds, one being of Spanish descent and the other Caucasian, there was a notable difference in sensitivity and humility. A medical provider recognized himself as an outsider and spoke of how he positioned the interviews with patients from a place of curiosity (Kauffman, 1994).

> *...and sometimes you just get hints of, sort of cultural behaviors that come up in regular conversation, so I look for opportunities to bring that up as a segue into, might I be missing something. You know, if I'm not looking…is there a cultural lens that you might be looking through that I don't, I'm not aware of, I'm curious about that. I think if you're curious and then, that is a, you know you're, then there are opportunities that present itself. You have to be thinking about it.*

Louisa discussed a gap in the approach to pain assessment as a category of *Hurdles and Hindrances* that was wonderfully illustrated by the story of a recent client.

The premise is that healthcare providers need *not* ask if someone is having pain – as noted above this might not be readily revealed. Instead we need to assess function:

> *I had a woman come in with a walker. ...Looks like Barbie, beautiful girl, comes in with a walker, but she's holding a cake, because people… we don't give prices but people give us donations. So she comes in with a cake and she parks her walker there, [pointing to the living area]. First time in the house.*
> *We ask, "Are you hurting?"*
> *She says, "No."*
> *We ask, "Why are you using the walker?"*
> *And she says, "Well, if I don't use it I'll have pain. I have to use it."*
> *And so, like when you deal with people that are very pride oriented that say they have pain, to say that they need help, it's a struggle. If you ask them, "Are you okay?" They are going to say, "I'm okay." They become almost like chronic liars. Like they can see they're sitting like in agony, but "I'm okay." How do you ask for help? And when is it okay to ask for help? And, if it's something that as a culture you're not accustomed to doing, you're not accustomed to saying that you need help or that something is not okay. If something's not okay then you should be able to fix it yourself.*
> *Ask them more direct questions.*

It was interesting to note when the medical provider was asked to describe how he assesses pain, he specifically addressed function. His recounting reflects sensitivity to the issues related to the theme *Pain Is More Than Physical,* specifically the category of meaning. This provider recognized the unique meaning that may be held of Hispanic men and women when there is pain-related loss of function. He beautifully illustrates a discussion about their pain – a dialogue rather than a checklist:

> *I try to talk about, you know, the function. What impact it has on their lives. I try to respond empathically, "So that sounds terrible, Oh, how is it affecting you? Are you able to do the things that are important?" I ask, "Can you speak more about that?" ...Asking open-ended questions: "That seems, you know, terrible to me. Can you speak more about that?" And just try to ask questions where they feel free that they can speak about it. So, I start talking about pain and then I let them lead me and follow their lead and then ask about things. And the, the spiritual parts of it, the social, those come in in those questions, so like having to do with function, so somebody's like, "I can't even get out of bed 'til noon." And then I'd say,*

> *"My God. If I couldn't get out 'til noon I don't know what I'd do. How do, how's, what does that mean? How has that changed your life?" You know, so you kind of again follow their lead. And we get into a long discussion. Of course, I manage to get in the more temporal variations that include what we typically look at – severity, location, radiating effects, neuropathic versus somatic and visceral; All the different qualities of pain.*

Situating a discussion of pain within a cultural context, a category of *Ways People Cope*, a medical provider shares insight into the complexities:

> *...are we seeing it through their eyes and what impact is that, does that have and how can we even address barriers when we don't even know how they're viewing things? I mean there may be barriers that we don't even think of. You know, because of the way that they culturally are approaching, you know something to do with pain. Again it may mean that somebody's not a whole man or something, and we're not even addressing that part of that. So that can be a barrier in itself. You know so it's very complex… What is interesting to me is that we may not know what we don't know. I mean we're using our epistemology – so there may be a subtle separate base of knowledge and that's tough.*

A final connection to themes and categories made by Louisa, the curandera addressed communication and the environment of care, as part of *Hurdles and Hindrances*. People go to providers in unfamiliar settings and with varying degrees of feeling safe and nurtured. Through personal experiences and reflections from her patients, Louisa had a general sense that lack of cultural sensitivity still pervades care.

> *...what happened with my grandmother and the lack of communication, her cultural values, that sometimes people can come from a very loving, caring place but if they don't understand the culture, what's happening, not to really have a full grasp, but where is it's like I see some of my patients now that they can tell me a lot more. But yet I can't call the doctor and be like, "Hey…do you know what I mean?" Because I don't know that the doctor's gonna value me.*

All providers recognized the influence of environment of care, addressing it in different ways. One felt it important to create a welcoming environment for patients that started from the waiting area, to the front staff and nurses. This was an important feature

of his practice. The other provider related environment to the creation of a safe supportive atmosphere. This provider found body language; genuine, compassionate engagement; and reflective open-ended questions could serve to instill a sense of safety and acceptance, which are fundamental to healthy communication:

> *I work very hard on making it so that's… the way you present that, the way you use your body with that, that, you want to invite them so they don't feel badly or frightened you know.*

The provider interview excerpts relate to aspects of both research aims, contributing to the larger construct of Hispanic's/Latino's experience of CRP. Lives are complex, as are interactions with providers. Each individual brings their own biases and positions to construct understanding. Greater interplay of the various overlapping categories and gaps will be discussed in Chapter V.

Family Caregivers

A husband of more than 35 years, a female partner and a sister were present and actively engaged during the interview with their loved ones. The husband had nearly as much to say as his wife. He was an active caregiver and manager of her care. He knew dates, provided historical details of the many steps that were taken in their rural community to try and address her pain, and then their journey to care in Albuquerque. This couple elected to reside less than a mile from the cancer center. They had lived in town far past the point of treatment completion and were afraid to return to their community for fear she would not receive the care needed. He spoke many times of the "nightmare" of watching her in pain and he had a sense of responsibility for getting her comfortable. He was a vocal advocate in her care.

> *....squeaky wheel, I believe in that strongly. And, I mean, the staff both in the hospital and clinic, they are overwhelmed. That big ole building they have – it's nice, but where are the staff? I have a good rapport with whoever, and I know I have a very good personal relationship with them, but I bitch about it, and you know, I'm a squeaky wheel. That nightmare.....I wasn't going to let that happen again.*

Both other caregivers spoke in their own ways of advocating and realizing the need for support and a voice on behalf of their loved ones. The tenor of the need to advocate relates to the notion of poor communication, fitting within the theme of *Hurdles and Hindrances*.

> *...I feel she was mistreated. I tried to massage and get her comfortable as much as I could, and you know, I don't know how her pain was. I would stay with her in the hospital. I even had to fight with the doctor. He told me, "Well, how do you know what pain she's in?" I see her! I see her with all her pain. I know what she needs by me taking care of her. It's kinda ridiculous, you know?*

Edgar's partner also shared examples of how she had to advocate for him during his many hospitalizations. An additional feature that emerged from this interview was her role at coaching and encouraging him. She spoke often on his behalf, raising concern about his usual level of pain. As the interview unfolded, she continued to encourage him and subtly developed a new plan for him. She seemed to capitalize on features of the discussion that she then could use to change his medication routine. Edgar had voiced many misconceptions and concerns about the side effects of the medication. This had created barriers to taking the medication, leading to significantly impaired function. She exploited these in a positive way to change his behavior.

A final example of the need to stay vigilant, advocating and addressing the challenges of providers' lack of assessment came from a participant's husband. He was

addressing his wife's pain related to the surgical removal of a side of her chest wall and ribs.

> *She* [the doctor] *was a nice* [provider] *and she would let us talk about her pain, but it was obvious she doesn't like that stuff* [pain medication]; *she* [the doctor] *wants her off them. And I wake up in the morning because I hear her moaning in pain. I just couldn't understand* [why she wanted her off the pills].

The major thesis from the three caregivers centered on advocacy and support. The pattern of their contributions related to that of support, a key feature of *Ways People Cope*. In addition, speaking on behalf of their loved ones resonates with deficiencies that are embedded in *Hurdles and Hindrances*. Specifically, the need to advocate was rooted in a lack of attention to pain assessment and accountability. I now describe the final source of data for this study – medical record documentation of cancer-related pain and how findings align with the research aims.

Medical Records

Medical records for all 14 primary participants were from clinic settings that used electronic medical records (EMR). Specific goals were to examine who was speaking about pain, how they addressed the pain, and what actions were taken to manage pain. Additional information was reviewed that related to specific medications used to treat pain.

Table 20 describes the questions that guided medical record queries as they related to both research aims. I explored how healthcare providers constructed experience and communicated that through interactions with patients, either documentation of phone contacts or in person clinic visits. Approximately 10 hours was spent reviewing documentation of the last several interactions between healthcare

Table 20

Medical Record Chart Abstraction

Research Aim	Operationalizing in Medical Record	Guiding Questions *
Explore dimensions of the CRP experience among Hispanics / Latinos.	How the healthcare providers construct the experience of an individual's CRP as reflected through text (Medical Record)	1. Who is talking about the person's pain in the medical record? 2. What means are used to assess the person's pain? a) Physiologic Descriptors b) Psychosocial/Affective Descriptors c) Intensity Rating 3. What means are used to manage the person's pain? a) Pharmacologic b) Nonpharmacologic
Describe how local, provider and system context intersect with the experience of CRP among Hispanics/Latinos.	Evidence of barriers, obstacles and other factors in the environment that influence living with CRP through text (Medical Record)	1. What evidence is recorded that addresses possible system barriers or misconceptions or lack of cultural awareness related to the discussion and treatment of pain?
* Review last 3 months of pain management		

documentation from both phone contacts and in-person clinic visits. I queried the record providers and their patients who participated in the study. This review included until I found the most recent evidence of pain care or documentation related to pain. Sometimes pain was only evident by searching through their medication lists and finding prescription renewals or reviewing a list of their current medications. Once this was identified, I reviewed the previous 3 months of data.

All levels of providers were found to be recording pain including medical assistants, nurses, nurse practitioners, and physician providers. The majority of pain description was captured by using intensity rating scales (0-10), but this was not consistent. A numeric rating scale was found in 50% of the records with the remaining

having a smattering of descriptors. There was not common language. Table 21 exemplifies the language used to describe the pain as it applied to three assessment components. Each of these descriptors was seen only once across all of the charts. In other words there was wide variation in the choice of which aspects of a pain assessment to include in the record, who was recording it and what language to use. No single record contained all of the features of a standard comprehensive pain assessment, nor were basic assessment elements of rating pain intensity, identifying a location and describing quality characteristics consistently present across all records.

One exception did capture some of the key elements, including a review of current medications, reports of relief obtained, location of pain and interference with function. Most common were irregular pieces of data seemingly disconnected from any

Table 21

Evidence of Pain Documentation

Chart Abstraction	Assessment Domain	Exemplars
Who Charted All levels of providers	Intensity Rating	Numeric Rating Scale 0-10 Descriptors: *'Severe',' Stable'* *'No reports of pain'*
Comprehensive Pain Assessment Absent from all records	Location	*'All over'* *'Generalized'* *'Pelvic'* *'Ribs'*
	Quality or Function	*'Tingling'* *'Neuropathic'* *'Numbness'* *'Burning'* *'Trouble Breathing'*

other piece of information. No clear plan linked pain rating, description, treatment and follow up plan in any entry.

In addition, there was no evidence of other aspects of pain such as impact on function, psychosocial or spiritual realms. An isolated finding of anxiety and depression were recorded in one initial history with the notation that the patient's neuropathy was improving with no further discussion of any pain. Again, a disconnected and incomplete reflection of pain was notable.

Regulatory forces drive the documentation of prescribed medications making it easier to capture what medications the participants were receiving. In spite of accreditation-related requirements mandating documentation of pain assessment, a paucity and inconsistent evidence of such were found. No recordings of prescribed nonpharmacological interventions or hints of patient teachings regarding medications and self-care strategies were noted in the medical records.

These findings demonstrate alignment with the patient reports categorized as *Hurdles and Hindrances*. Specifically the lack of standardized pain assessment as reflected in documentation is consistent with the thematic category of Pain Assessment and Treatment Accountability. The lack of attention to documented pain care in a population of patients with known pain resonates with the primary participants' accounts and of their challenges to achieving pain relief. These findings also are congruent with the advice that some participants made relating to pain assessment.

Evidence in the medical record that reflected the second research aim was predictably difficult. There was a lack of evidence of a systematic approach to documentation of pain assessment and management. There was lack of clarity in

identifying who was accountable for providing which part of the pain care. For example, a chart reflected hand-off gaps between the nurse-provider seeing the patient, another level provider, pharmacy and the oncologist – all practicing within the same office. In another case someone outside of the oncology clinic was managing the pain but there was no written reflection of communication between providers regarding the pain care. Also of interest, in one instance an opioid contract was in the record however there was no rationale for such a plan documented. This record reflected no evidence to justify writing an opioid contract, such as an active or past drug history nor drug related behaviors.

Another record demonstrates a similar issue of interprovider gaps in communication. A nurse recorded pain location but no rating then referred the patient to the physician assistant to order a diagnostic test. The physician later saw the patient yet there was no documentation of assessment of pain in spite of the nurse notation and referral, and the fact that this patient was on analgesics. Review of these documented activities should summons a more comprehensive pain assessment and plan by the medical provider.

Taken as a whole, and in light of the second research aim, the medical record offered a limited description of pain in any of the participants. Medical recordings often are fragmented and incomplete 'stories' of care however they serve as a historical timeline for each individuals care needs and necessary conduits of communication between providers. The near absence of mention of pain in light of national standards and professional evidence-based guidelines, speaks to a lack of prioritization of pain assessment and care. This is further disheartening in light of the fact that all of these participants had a well-established trajectory of pain and medication use.

Summary of Analysis

This chapter has captured three themes and associated categories constructed from primary participants, caregivers, providers, and a focused medical record query. Figure 4 was constructed as a way to visualize the linkages and associations with the research questions. This model serves as an operational framework for beginning to consider major themes and relationships. Data from the caregivers, providers, and medical records triangulate with the major themes developed through the primary participant interviews. No new categories were established through these additional data sources; rather they were seen as fitting within an existing framework.

Two of the themes, *Pain Is More Than Physical* and *Ways People Cope*, related to Research Aim 1, describing the experience of CRP. The third theme, *Hurdles and Hindrances* aligned with Research Aim 2, describing social, local, provider or institutional influences on the participants' experiences. Situated within the theme of *Hurdles and Hindrances* were overlapping patterns and linkages to *Pain Is More Than Physical*. Interviews of the participants, professional providers, and family caregivers and the medical record reviews were probed for congruence with the developed themes. A discussion of these linkages and experiences from the researcher's perspective is presented in the final chapter. The final chapter seeks to illuminate the patterns across data sources and how these reinforce or contradict recent literature.

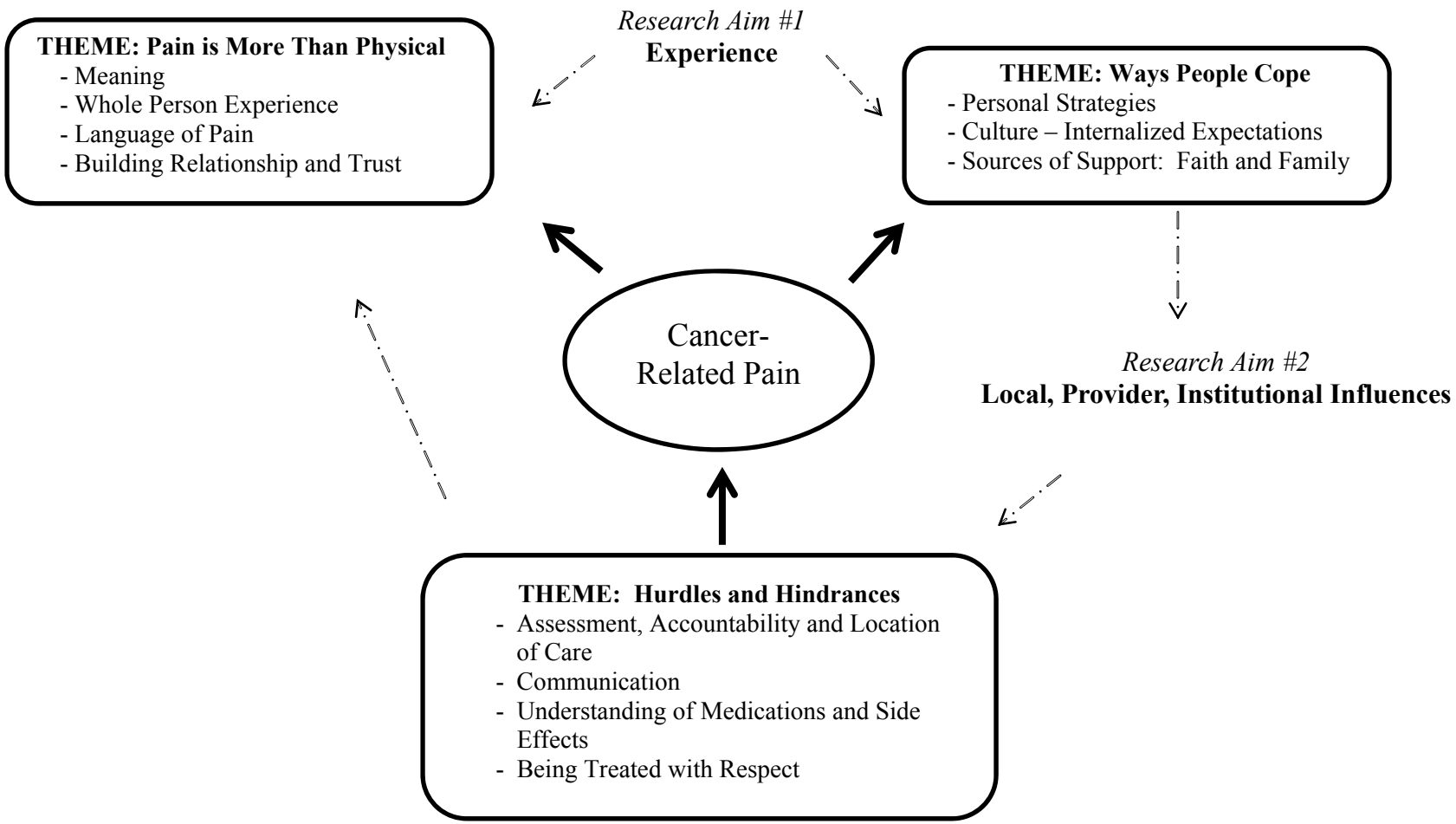


Figure 4. Operational Model of CRP Themes and Categories Among Hispanic/Latinos

CHAPTER V

DISCUSSION, LIMITATIONS AND NEXT STEPS

"Paradoxically, we know more and doubt what we know. Ingeniously, we know there is always more to know."
(Laurel Richardson, In Denzin & Lincoln, 2003, p. 518).

Reflecting on some of the demographic features of this study sample, there were some notable differences than in the broader cancer population. Most of these participants were second generation residents, having parents or grandparents traveling from Mexico, settling and raising families in New Mexico. This is consistent with reports that in 2011, 63% of New Mexican Hispanics claimed Mexico as their place of family origin (PewResearch Hispanic Trends Project, 2014). In this study these numbers were higher with 85% reporting Mexico to be their home of origin.

These participants were younger (average age 55) than the general cancer population; the highest incidence of cancer reported nationally is over the age of 65 (Howlader et al., 2014). It is notable that the Hispanic population is generally younger in New Mexico with the average age of 30 years (PewResearch Hispanic Trends Project, 2014). More of these participants were unemployed than other Hispanics in New Mexico (14.2% vs 10.6%, respectively). However, they all had a cancer diagnosis and many were receiving treatment during the time of the interviews (NCI, 2013a).

Study participants had a slightly higher than average income ($41,538) compared to other Hispanics in the state ($40,963) and only 14% of the sample had not completed high school compared to 28% of all Hispanics in New Mexico (NCI, 2013a). A final demographic comparison was made by insurance coverage. All 14 participants had some type of health insurance, (state, federal or private), exceeding the 25% coverage reported for New Mexicans (PewResearch Hispanic Trends Project, 2014). In summary, this sample of Hispanics in New Mexico was younger and more affluent (as reflected by higher education, slightly higher incomes, and holding health care insurance) than the general Hispanic population in New Mexico. These facts are informative and contribute to how results may be interpreted, but I would not characterize these participants as wealthy. With the exception of insurance status, these participants remain below national and state figures for income and education (NCI, 2013a).

Examination of disease conditions revealed very few comorbidities in this sample. This is in alignment with national reports on prevalence of comorbidities and cancer (NCI, 2013c). Cancer sites varied with no diagnosis represented far more than another, supporting the evidence that cancer pain exists across primary tumor sites (Higginson & Murtagh, 2010). Cancer treatments reported were typical of the general population with surgery being most common, followed by adjuvant chemo or radiation therapy.

The one feature that was shared by most in this study was stage of disease; many had advanced later stages of cancer at the time of the interviews. Research consistently reports a greater prevalence of pain associated with progressive disease. (Foley, 2010;

Higginson & Murtagh, 2010). It is important to note that all of the participants either had completed or were still actively receiving treatment. They were not receiving end of life or palliative care or predicted to be at the end of their life, even though two died during the course of the study and others within a year following data collection.

Results from these interviews demonstrate how cancer-related pain is situated in a larger framework including what pain means to each individual; the challenges of navigating pain as a regular part of daily life; the cultural influences on behavior and interpretation, relationships, and provider communication; and the complexities of seeking relief from pain.

Richardson (2003) challenges researchers to remember that there are many sides to a phenomenon, and rather than organizing in a linear fashion, a fuller presentation of experience can emerge by creating a prism, of sorts, where themes converge. Data were gathered through interaction, questions, observation, reflections, and a review of text. Abundant, thick, rich data require careful and considered unbundling and reconfiguring within the context of the research study. Foucault (1994) suggests that the process of analysis should include establishing correlates with other statements, making connections between the various forms of data. In this study, different data sources were examined for overlapping, contrasting, or contradicting data.

The findings have been organized by the research aims, and they are discussed in this chapter in relationship to previous research. A reflection on limitations follows a discussion of the findings. Here I address some of the concerns regarding the limited data sources and how I attempted to achieve verification, corroborating with past

knowledge while adding the findings from this study and moving forward to advance our understanding of CRP (Meadows & Morse, 2001).

Included in this chapter is an account of the challenges I encountered gaining access to participants. While not directly linked to the findings of this study this experience lends itself to some important contemplation on conducting research in diverse populations. Finally the chapter concludes with next steps and recommendations for practice, research and education.

Discussion: Findings in Alignment with Past Research

Traditional Framework of Pain

Themes and several categories that developed in the analysis parallel much of our current construct of pain and providing relief. Evidence-based guidelines exist to guide clinicians in providing quality comprehensive pain care (ACS, 2004; Gordon et al., 2005; NCCN, 2014; ONS, 2011; van den Beuken-van Everdingen, 2007; WHO, 1996). These guidelines stress the importance of a skilled assessment of pain, including exploration of meaning, temporal components such as description and intensity, factors that improve and aggravate pain, and the functional impact of the pain. Over 2 decades ago Ferrell and colleagues (1990) proposed a formative framework for the pain experience. This model, summarized in Chapter II includes many of the elements heard in the current study. Bates' model further integrates culture into the biocultural model for understanding pain (Bates et al., 1993). The first research aim of understanding experience captured many features of both of these models as well as what others have reported of cancer-related

pain among Hispanic/Latinos and others with CRP. Below is a summary of congruent findings.

Meaning of Pain

An unmistakable finding of this study was the multifaceted meanings of pain as experienced by the participants. Features of the experience of CRP were strongly tied to the meaning of that pain. As revealed during many interviews, while talking about a particular aspect of their pain, soon the word cancer replaced the subject of pain. This notion of pain as one with the cancer, a symbol or branding of sorts, was a common discourse during these interviews, even when the subject was focused specifically on pain, cancer emerged. The interviews were about their pain, cancer-related pain, but all interviews had as much dialogue around having cancer as it did about the pain. Much of the past literature has included the importance of exploring meaning of pain and its role in how CRP is perceived. Table 22 summarizes the thematic categories that were described within the theme *Pain Is More Than Physical*. These categories are described and associated literature serves to validate and support the categorical findings. The percentage of time that participants described elements of the individual categories is presented.

Mead and Bower (2000) proposed a patient-centered model of care that was used to organize themes developed from a systematic review of qualitative studies on adult cancer pain (Luckett et al., 2013). *Patient as person,* one of the five dimensions of their model captures individual meaning. Factors of experience such as economic, culture and

Table 22

Pain Is More Than Physical

Thematic Category	Definition	Literature Validation	Percentage Present in Analysis by Data Source
Meaning	-Pain signifying the underlying disease - a life-threatening illness -Pain signifying the end of life	Anderson et al., 2002 Callister, 2003 Campbell et al., 2009 Cleeland, 1984 Fairchild, 2010 Villarruel & Ortiz de Montellano, 1992	Participants: 79% Field Notes Providers: NA Caregivers: NA
Whole Person Experience	- Pain affecting many aspects of life: relations, function, responsibilities	Beck et al., 2009 Juarez et al., 1998 Juarez et al., 1999 Im et al., 2007 Luckett et al., 2013	Participants: 75% Providers: NA Caregivers: NA
Language of Pain	-Using affective, cognitive, functional language to describe pain	Campbell et al., 2009 Juarez et al., 1998	Participants: 93% Providers: NA Caregivers: NA
Building Relationship and Trust	-Provider interactions crucial to developing trust, improving quality of interactions and contributing to medication adherence	Becket al., 2009 Luckett et al., 2013 Vallerand et al., 2007	Participants: 57% Providers: 66% Caregivers: 100%

history are considered part of the personal context of experience. Luckett and colleagues reported strong support for the importance of a personal interpretation of pain.
It seems that while findings from this study coalesce with the idea that a personal interpretation of pain is central to care, the wholeness of the pain experience for the individuals in this study was so deeply connected to their construct of cancer, there was no untangling. The next step is to consider how inquiring about and addressing the meaning of pain become a routine part of our pain discourse with patients and families, and how providers position this interconnection in terms of the sensitivity with which pain is assessed.

Description of Pain

An abundance of literature can be found addressing the complexity and multiple domains of pain, extending beyond a linear construct of zero to ten (ACS, 2005; Berry & Dahl, 2000; Clausen, 2009; Cleeland, 1984; JCAHO, 2000). These descriptions of a very personal experience of what pain means have told so much more than a numeric rating ever could reveal, providing a rich and vivid reminder of elaborate dimensions. Pain descriptors in this study were more emotive and highly descriptive, capturing affective, functional, and physical realities of experience – quite dissimilar to our one-dimensional approach focused on severity. The descriptive texture of pain was vivid and informative, for example: *"a nightmare," "emotional," "like my leg was trying to break itself,"* and *"toes just curl up.*" Juarez et al. (1998) and others have described variation in the language of pain among Hispanic/Latinos from different Latin-American countries

(Campbell et al., 2009; Haozous & Knobf, 2013). These findings suggest that there is room to expand our assessment strategies beyond a linear analog scale, currently considered the gold standard (Booker & Herr, 2014). While the aim of such measures is to quantify pain such that decisions and efficacy of interventions can be evaluated, there can be incongruence between providers' need for quantification and the reductionistic nature of such a measure. The complexity of pain when it is *"scary*" or it is *"in my heart"* is difficult to distill into a number. Broadening the scope of how pain is described beyond a number captures nuances and different domains of experience, potentially enhancing the repertoire of interventions (Davidhizar & Giger, 2004; Zinke, 2007).

Pain was spoken of in a way quite different from how the healthcare team directs dialogue around pain. Well-intended and necessary professional standards exist to structure the discourse of pain assessment in a fairly scripted manner. For the most part this framework exists to help us speak in a uniform, predictable manner amongst ourselves and to guide treatment decisions. It is worth noting that when at the directive of the participants, the way to talk about pain, to quantify it, was far less quantitative. This incongruence suggests a window of possibility to integrate the personal languages of pain in a way that improves pain care outcomes.

Culture

Well-aligned with the first study aim of understanding the CRP experience, culture was evident in nearly all of the categories within the theme *Ways People Cope*. I would like to preface this summary by clarifying that coping is a collection of actions that

people do in response to a given situation (Pearlin & Schooler, 1978). In this case the things people did to navigate the CRP were often linked to cultural factors. Table 23 summarizes components of the second thematic category - *Ways People Cope.* Each category is defined and validated with supporting literature and the percent of time these were identified in data analysis are reported.

Cultural influences and patterns of experience can be seen in the strategies developed to manage pain; one's upbringing (such as enduring and behaving in ways described as strong); and the centrality of family as part of the pain experience (such as trying not to worry others and minimizing the focus on pain by frugal disclosure). Numerous investigators have described features of these and similar constructs as part of the Hispanic/Latino culture (Campbell et al., 2009; Davidhizar & Giger, 2004; Im et al., 2007; 2009; Maduro, 1983; Villarruel, 1995; Villarruel & Ortiz de Montellano, 1992).

Fundamental to ways of coping were the importance of family, connection, and communication. Data from all sources except the medical records provided similar referencing to family and connection. Each from her/his own perspective acknowledged family as central to the experience as a patient, as a caregiver, or as a provider. Field notes corroborated the larger circle of effect by observations in the homes that represented inclusion and the presence of others. All of the interviews included frequent references to family and their importance in how they coped with cancer pain. The core position of family, or *familismo*, the desire and willingness to provide support through what is often a shared experience, is well documented in previous research with CRP

Table 23

Ways People Cope

Thematic Category	Definition	Literature Validation	Percentage in Analysis by Data Source
Personal Strategies	-Everyday ways to relieve pain: sleeping, distraction, positive attitude	Campbell et al., 2009 Duggleby, 2003 Im et al., 2007; Juarez, 1996 Juarez et al., 1998 Kwon, 2014 Marin & Marin, 1991 Paice & Ferrell, 2011	Participants: 93% Providers: NA Caregivers: NA
Culture**:** Internalized Expectations Sources of Support	-Family as central to the experience -Importance of their inclusion -Family became a unified body centered on how best to aid their loved one -Faith / Spirituality source of grounding	Campbell et al., 2009 Cleeland, 1984 Duggleby, 2003 Im et al., 2007 Juarez et al., 1999 Marin & Marin, 1991	Participants: 100% Field Notes: Faith Religious artifacts noted in 5 homes Providers: NA Caregivers: 100%
Culture: Internalized Expectations Convivir	-Translates to "coexist" and is enacted as a way of helping each other, interacting, and sharing experience	Ayón & Villa, 2013 Duggleby, 2003 Maduro, 1983 Villarruel, 1995	Participants : NA Caregivers: 100% Providers: NA
Culture: Internalized Expectations Heat or Cold	-Temperature is a symbolic reflection of body imbalances and is used to restore equilibrium	Juarez, 1996 Juarez et al., 1998 Kay &Yoder 1987; Maduro, 1983;	Participants: 40% Providers: 66 % Caregivers: NA
Culture: Internalized Expectations Silent Suffering	-Enduring, Machismo or Stoicism -Suffering in silence -Being brave, Sucking it up	Anderson et al., 2002 Im et al., 2007 Juarez, 1996 Juarez et al., 1998 Villarruel, 1995	Participants: 86% Providers: NA Caregiver: 33%
Advocating	-Caregivers perception of lack of quality communication and pain management by providers	Luckett et al., 2013	Participants: NA Caregivers: 100% Providers: NA

(Campbell et al., 2009; Duggleby, 2003; Im et al., 2007; Juarez, 1996; Juarez et al., 1998; Marin & Marin, 1991).

For many there was both a desire to include family and loved ones in care and attempts to shield them from worry by creating protective behaviors. As seen in this study, three interviews included a family member; their inclusion in the interview was assumed. In other cases, family was notably not far away, gently checking in during the interview either by physically entering from another room during the interview or by calling when they knew their loved one was being interviewed. Juarez and colleagues (1998) reported a similar experience during home interviews in which there was "often" a family member present (p. 268). In another study conducted among Hispanics with CRP, researchers reported a theme from their interviews of "*family is more important than cancer pain"* (Im et al., 2007, p. 865). Participants spoke quite strongly of how family became a unified body centered on how best to aid their loved one and how that support was paramount.

The concept of *convivir* means that family is cohesive and shares the joys and challenges of life. *Convivir* translates to "coexist" and is enacted as a way of helping each other by interacting and sharing experiences (Ayón & Villa, 2013). A precept in understanding the Latino folk healing system of curanderismo includes the assumption that cure requires the participation of the entire family (Maduro, 1983). Findings from the interviews of the current study echo these sentiments and hold important implications for clinical practice.

In tandem with the primary participants' contributions, analysis of the three caregiver interviews reflects another aspect of family – their desire to advocate and support their loved one. Their expressions of experience focused most acutely on speaking up for their loved one, sensing that there was a lack of quality communication and pain management by providers and a need to advocate. Vallerand and colleagues (2007) did not examine barriers to pain care specifically among Hispanic caregivers; they did find that for caregivers a gap in pain knowledge was a significant barrier to adequate pain care. What I am suggesting is that family members need adequate knowledge to more effectively advocate for their loved one. A systematic review of qualitative studies examining barriers and optimizing care strategies for cancer-related pain across populations similarly concluded that engaging family caregivers in a way that empowers them with knowledge and control to assist in self-managing care is an essential shift in order to improve outcomes, such as communication, and ultimately the quality of pain care (Luckett et al., 2013).

The meaning of heat and cold as it pertains to illness has been reported in earlier studies (Juarez et al., 1998; Kay &Yoder 1987; Maduro, 1983). Temperature is a symbolic reflection of body imbalances and is used to restore equilibrium. Some participants in this study reported the use of heat or cold to help with pain, but it was only the curandera who spoke of its cultural rootedness.

Upbringing seemed to implicitly guide how pain was expressed. The cultural norm reported as "enduring," "machismo," or "stoicism" has been reported for many years in studying pain among Hispanic/Latinos (Anderson et al., 2002; Im et al., 2007;

Juarez, 1996; Juarez et al., 1998; Villarruel, 1995). While not a central theme in the current study, men and women both described enduring pain as something that was learned from childhood, seemingly contributing to their experience of CRP. Previous studies reported stoicism as an aspect of suffering; other research also identifies the importance of fatalism (Campbell et al., 2009; Juarez; Villarruel). While the experiences and stories were poignant and often emotive, fatalism or a belief that pain was part of their destiny was not an evident part of this theme. Rather, there was a current of expectation that pain could be addressed – perhaps not completely but definitely better than what they experienced in most cases.

Recognizing the centrality of family and how culture influences expression and coping with pain provides support for Bates biocultural model (1987). In this model pain perception is produced by a complex interaction of the physical and learned from within social groups – primarily the family. What people presently experience as pain is tethered to their past experiences and the meaning placed on those events. Thus, understanding people's past experiences needs to hold a central place in comprehensive assessment and management. Campbell and colleagues (2009) recognized a gap in understanding how Hispanic/Latinos cope with pain. This study has contributed to a body of research by reinforcing some aspects of how Hispanic/Latinos navigate CRP and illuminating aspects of coping that were important to these participants.

Obstacles and Barriers to Pain Relief

The findings that coalesced with the second research aim describing how local, institutional and provider-level factors influenced the experience of CRP largely coalesced into the theme *Hurdles and Hindrances*. Much of the discourse relating to obstacles or barriers to pain care involved aspects of provider interactions. Providing complete and competent pain assessment, establishing accountability for pain care, effective communication and education about pain medications and side effects and being treated respectfully were thematic categories aligning with this theme. Table 24 describes these categories, validates findings as they align with previous research and reports the percent of time these categories were identified in the current analysis.

Accountability for Pain Care

A lack of comprehensive assessment, a lack of accountability for ongoing pain care, and the location of where participants received care were reported obstacles to effective pain management. While not in specific language, the interviews revealed frequent descriptions of what I have categorized as a lack of comprehensive pain assessment.

Determining the underlying source of cancer pain can be difficult and is not always evident, but in this study all of these participants had CRP, making it more distressing to find a lack of consistent assessment and management. These findings are consistent with longstanding and recent publications addressing the gap in provider assessment for managing CRP reported across cancer populations (Beck et al., 2009;

Table 24

Hurdles and Hindrances

Thematic Category	Definition	Literature Validation	Percentage Present in Analysis by Data Source
Pain Assessment Treatment Accountability Location of Care	-Lack of attention to pain assessment -Lack of responsibility to address pain -Place of care made a difference in quality	Beck et al., 2009 Campbell et al., 2009 Cleeland et al., 1994 Cleeland et al., 1997 Duggleby, 2003 Im et al., 2007 Juarez, 1996 Juarez et al., 1998 Kwon, 2014 Marin & Marin, 1991	Participants: 86% Caregivers: 100% Providers: NA
Communication	-Poor provider communication contributed negatively to pain relief, poor medication adherence, & added to distress	Deandrea et al., 2008 Fairchild, 2010 Im et al., 2007 Juarez et al., 1998 Kwon, 2014 Luckett et al., 2013 McNeill et al., 2004 Paice & Ferrell, 2011	Participants: 80% Providers: NA Caregivers: 100%
Medications and Side Effects	-Lack of understanding of medication management, unacceptable or inhibiting side effects	Anderson et al., 2004 Cohen et al., 2008 Kwon, 2014 Liang et al., 2008 McNeill et al., 2003 Vallerand et al., 2007	Participants: 93% Providers: NA Caregivers: NA
Being Treated with Respect	-Relationship, Trust are critical -Believe Patients -Include Family in Care -Treat the whole person	Beck et al., 2009 Kwon, 2014 Luckett et al., 2013 Paice & Ferrell, 2011 Vallerand et al., 2007	Participants: 57% Providers: 66% Caregivers: NA
Advocating	-Caregivers perception of lack of quality communication and pain management by providers	Luckett et al., 2013	Participants: NA Providers: NA Caregivers: 100%

Campbell et al., 2009; Juarez et al., 1998; Kwon, 2014; Luckett et al., 2013; Paice & Ferrell, 2011).

Another dimension of gaps in assessment and accountability came from the medical record reviews. Previous research has not captured medical record documentation of pain as was done in this study. One can speculate about the many reasons for less than complete documentation. However, the glaring absence of consistent, reliable, and congruent written summation of patients' pain potentially symbolizes a reduced prioritization. Evidence of pain assessment was sometimes found with few remnants of professional guidelines being operationalized in the form of documentation. These findings aligned with individuals recounting their experience of pain, its assessment, and treatment.

Some people described their oncologists as reluctant to continue treating pain once their cancer treatment was complete, instead transferring care back to their community primary care providers who they perceived often felt ill-equipped or uneasy about assuming this responsibility. These experiences speak to the ongoing challenge of and gap in efficient continuity of care. Glare and colleagues (2014) suggest that early identification of who will be primarily responsible for pain care and medication management for cancer survivors is paramount. They suggest that the lack of such continuity and accountability is the responsibility of healthcare systems. It is within institutions that these standards should be made and upheld.

Communication

Facets of communication resided in both study aims (Erickson, Badiane, & Singer, 2013). As a component of the theme *Pain Is More Than Physical*, communication was tied to the importance of building trust and relationship. It also was described as part of *Hurdles and Hindrances*, reflecting how poor provider-patient communication influenced medication management and created patients' concern of being judged by their providers.

Making a connection and feeling a sense of engagement with providers were significant underpinnings in this analysis. Researchers with Hispanic/Latino populations continue to report the importance and critical nature of developing relationships (Anderson et al., 2002; Campbell et al., 2009; Im et al., 2007; Luckett et al., 2013; Mead & Bower, 2000; Mead et al., 2013). This was operationalized early in the interviews. People I interviewed embodied the spirit of *bienvendios*, the sincere desire to welcome you in (Bordas, 2013). In the midst of the challenges and complexities of illness, treatment, and symptoms, there was a willingness to make space and time to share their stories with me.

Aspects of communication surfaced throughout the interviews and were represented across themes. Communication also came up when participants were asked if they had advice for others. Study participants gave recommendations not singularly directed toward an individual discipline; rather, their suggestions spoke more to the cultural framework of institutions and the social norms of people that provide care within them – that is, a systemic lack of individualized care. When participants perceived

communication to be good, their impressions of the pain care were also positive. The opposite was consistently true as well, meaning that when participants perceived poor communication there was implication of negative pain care.

Research findings have long reported shortcomings in provider-patient communication, targeting it for future scientific exploration. Unmet communication needs exist among all ethnic groups with cancer but have been disparate among ethnic minorities. Evidence exists that effective, interactive, and culturally congruent communication with patients and caregivers can result in positive health-related quality of life, positive psychological outcomes, and reduced healthcare system utilization (Haozous & Knobf, 2013; Mead et al., 2013). Maduras (1983) identified the importance of open interaction with "healers" as a precept of working with Latinos. Although Mead and colleagues' (2013) systematic review pertained to cancer care decision-making among ethnic and racial minorities, rather than pain care, some of their findings are compatible and applicable to the current study. For example, their findings pointed to the importance of provider communication and information giving as part of the shared-decision model of cancer care. This review found across studies there was a persistent need to engage more personally and attentively to the individual and develop culturally-sensitive communication skills (p. e26).

It is unfortunate that issues of provider-patient therapeutic connectivity continue. Therapeutic communication and connection are imperative to improving pain outcomes and compliance with treatment (Mead et al., 2013). The presence of positive and respectful connections with providers has been found to influence outcomes such as

cancer treatment adherence and symptom burden among patients and caregivers (Luckett et al., 2013; Meeker, Finnell, & Othman, 2011). The findings from this study are consistent with existing evidence reinforcing the important relationship between making human connections, treatment adherence, and clinical outcomes, yet unraveling the answer to how to effectively impact this central issue persists.

Family and Advocacy

Recent findings show that family members often lack the knowledge to effectively assist in care and concurrently providers lack a full appreciation of the importance of the caregiver's role in pain care (Luckett et al., 2013). While caregivers' experiences were not an explicit aim of the current study, their central role to the people living with CRP was recognizable and reinforced in previous reports (see Table 24). As reported by both caregivers and the primary participants, family aid in speaking up for their loved one was seen as a critical influence in adhering to medication regimens and providing foundational support for the person with CRP.

As reported in Chapter IV, a primary thesis was identified from the three caregiver interviews – that of advocacy. This was consistent with the review conducted by Mead and colleagues' (2013). They found family members to be important spokespersons during clinical encounters by facilitating communication and providing support. The three unintended family caregiver participants in this study echoed the position that family must serve to actively engage with providers on behalf of their loved ones.

In summary, I have attempted to illuminate ways reported obstacles or described

challenges in CRP care intersect with the second research aim. It is important to uncover system or provider attributes that perpetuate inadequacies in cancer-related pain care. Communication imparities, limited inclusion of family in care and confusions around accountability and responsibility for pain care reflect system and training flaws as well as individual and collective misalignment of priorities of pain care.

Another factor that influences pain care relates to overprescribing. The resurgence both in New Mexico and throughout the country of prescription medication-related unintended overdosing is an important concern and bears weight on undertreatment of CRP. The discourse of diversion must be part of treatment of all patients with pain, including CRP yet providers must recognize the risk of perpetuating undertreatment by over-correcting prescribing practices among persons with CRP.

It is important to caution against drawing universal generalities from what is reported in this study. However, many of the findings resonate with features of past research both with ethnic groups as well as general findings in CRP. Unfortunately, findings from this study echo a longstanding discourse of pain care with persistent flaws and weak integration of pain guidelines. Examples of such recommendations include developing better communication and congruence with patients; integrating culturally appropriate assessment tools; including family and lay caregivers in decision-making; and strengthening professional provider cultural awareness, training, and self-reflection (Campbell, 2009; Glare et al., 2014; Im, 2007; Juarez, 1996; Juarez et al., 1998; Luckett et al., 2013; Mead et al., 2013). Challenges remain as to how to incorporate these crucial elements into the existing structure.

Contextualizing My Journey - Further Outside Than I Realized

I felt it was important to provide a brief description of the challenges encountered during recruitment. While it is not uncommon for the recruitment process to be laden with delays, it seemed that the obstacles to identifying participants for this study were unexpected and is deserving of reflection. Kauffman (1994) describes being an "insider" as belonging to a particular group through which membership affords understanding (p. 179). In reflecting on what is really considered being an "insider" or an "outsider" in the context of this study, I had to ask myself, "Of what?" While I knew there would be steps to this process, I didn't realize how challenging they might be.

Beyond the official institutional sanctioning of research proposals, the real steps of "*getting in"* began at the front door of the clinics that agreed to help identify participants. I assumed that my existing relationships and networking, in place for many years, would serve to ease identification and access to the people I wished to interview. As an oncology nurse for many years, I have a broad network within the oncology community in Albuquerque and believed there would be ample support and assistance in identifying potential participants for this study.

On one level as a member of the professional community, I might be considered an "insider" seeking aid from within my network to identify participants. However, not being employed at these facilities seemed to position me as an "outsider." I considered myself a member of the professional community, yet barriers abounded in terms of access to the people who might be willing to tell me their story of cancer pain. Enlisting multiple creative strategies to reach participants often yielded little; I was simply not

prepared for the challenges I encountered in recruitment.

A critical flaw was assuming that established working relationships would yield greater buy-in from others, and efficient and timely referrals. (Gibson, Gibson, & Macaulay, 2001). There was abundant stated support for my endeavor. However, when it came down to it, referrals were scarce.

I worked for 1 1/2 years to recruit the final sample of 14 primary persons with cancer-related pain from four oncology practice settings in the urban area of Albuquerque. These four sites provide care to more than 50% of the cancer population in New Mexico. It was regularly perplexing as to why I faced such a recruitment challenge even though Hispanics/Latinos represent 47% of the New Mexico population and pain is not an uncommon issue in persons with cancer (US Census Bureau, 2014). Contrary to my actual experience, these factors seemed to suggest that the population was indeed available and would certainly prove a rather speedy accrual.

In pondering the complexity of access, I noted that many of the persons with cancer who participated referred themselves as a result of seeing public notices. While several people were referred from nurses and a patient navigator, many reached out themselves, eager to tell their story. In exploring the possible causes of slow recruitment I briefly considered that perhaps people didn't want to discuss their pain, but this contradicted my clinical experience; people want to talk about their pain when someone will listen.

These musings are my attempt to understand the reality of this rather difficult process of recruitment in an environment where I had forecast relatively little resistance.

The academic discourse of gaining access often focuses on strategies of integration and acceptance within a particular community or population. There is less formal and informal conversation on untangling the bureaucratic process leading up to working with a group. In the case of this study, the insider/outsider paradigm takes on more than one layer; rather it begins in the settings where cancer patients can be found. Traversing the layers of provider and system engagement proved to be its own microcosmic hurdle.

Somewhat later in the study, two additional sites were added to accelerate recruitment. These clinics represented an extension of an already widely-cast net. Both facilities were supportive and confident their clinic had such participants and would easily find the final number of participants needed to complete the study, a reaction not dissimilar to the original recruitment sites. After 3 months of maintaining regular visibility, meeting with various gatekeepers, and gentle yet dedicated reminding, not one single participant was identified from these clinics.

In her landmark study Kauffman (1994) describes phases of "getting in" (p. 179). I experienced the challenges of access as she originally intended: that there were stages and steps of gaining acceptance into groups outside the researchers' sphere. *Comadre a Comadre,* a grassroots organization providing ethnically and racially diverse peer support for breast cancer survivors, contributed to identifying potential study participants. I had a professional collaborative history with the executive director, and she paved the road for me to speak with some of the *Comadres*. The day I arrived a small table was encircled with women preparing mailings for an upcoming event. There was a tentative feel to their greeting that felt less than trusting of me initially, a polite yet somewhat

condescending welcoming that placed me as an outsider (Kauffman). That moment became a touchstone reminder of feeling separate; I was a member of neither the ethnic nor contextual group.

> *I went today to talk to a few volunteers about the study. Three were Comadres and I quickly felt the guarding and reserve my presence seemed to elicit. Somewhat sternly one woman stated, "We were told that when you arrived, we should put this away and listen to you." Being a bit startled by this remark, I wanted to communicate that I had no intention of disrupting their activities and quickly asked if I could help stuffing envelopes. Over the course of two hours, they were more receptive and curious about the study (Field notes, 9/10/2012).*

While the *Comadre* experience reflected the original application of Kauffman's (1994) construct of insider and outsider, I would suggest that "getting in" also resonated with the challenges more broadly of gaining access to participants, extending to the bureaucracy of the familiar culture of institution.

Findings in this study were consistent with previous reports that an individual's experience of pain is influenced by culture, community, larger societal positions, providers, and the healthcare system (Haozous & Tish Knobf, 2013; Juarez, 1996; Juarez et al., 1998; Paice & O'Donnell, 2004). In addition to what was found to be familiar in these interviews and themes, there was a shift in how to understand the importance, implication, and application of these themes. Embedded within these profoundly personal, generous, and rich findings were limitations.

Limitations

In this preliminary study there are recognized limitations. Spanish-speaking participants were not included in this study. Thus the findings best represent the group of New Mexican Hispanic/Latinos who were born in the US and are more acculturated, especially in terms of language. Spanish-speaking Hispanic/Latinos would have brought a much-needed perspective, perhaps being less aligned with and less assimilated into the dominant culture. Due to the practicality of conducting the study, that is, the interviewer did not speak Spanish, only English-speakers were included. Despite the potential limitation of not including Spanish speakers, as previously described in Chapter IV, some of this study's findings were comparable to a sample of Spanish-speaking Hispanics/Latinos with CRP in a previous study (Juarez, Ferrell, & Borneman, 1998). Examples include lack of behavioral expressions of pain ("suffering silently"), stoicism, and lack of information on pain medication.

As previously discussed, there is wide cultural variation within the very broad category of Hispanic/Latino. The sample of 14 is small and perhaps lacks many distinctions within cultural subgroups. Most of the participants were native to New Mexico, either first- or second- generation citizens. The gender profile of the sample was more weighted toward females (71%), therefore possibly underrepresenting the male Hispanic experience. A future research design could enhance diversity by targeting Spanish-speaking participants, including greater granulation of ethnic identity beyond Hispanic/Latino, and purposively accessing a larger male representation.

As I described earlier in this chapter, achieving the desired sample of primary

participants with CRP was a significant challenge. Controversy exists in determining a reliable and acceptable sample size. The literature emphasizes adequate sampling in qualitative research, although generalizability is not a primary goal (Baker & Edwards, 2012; Mason, 2010). Much of this literature suggests a standard number of 12-20 participants to be adequate (Bowen, 2008; Lincoln & Guba, 1985; Mason). Bowen claims the process of determining sample size in qualitative research lacks consistency and has practical weaknesses, suggesting that data saturation should guide sampling, not an arbitrary predetermined sample size. Guest and colleagues (as cited in Mason) analyzed their own data to determine when in the process of analysis they reached saturation. In their study, 36 codes developed from 60 interviews. Thirty-four of the codes were identified in the first six interviews with one more after the twelfth interview. When given a homogenous sample, meaningful themes and valuable interpretation may effectively be achieved in the first six interviews. Maliski, Connor, and Litwin (2012) had a similar experience when exploring ways Hispanic men communicate about prostate cancer. In their study, saturation was achieved in the first 16 of 30 interviews. The final 14 interviews served simply to verify their developing framework.

In earlier stages of data collection, the inductive methods of line-by-line coding and constant comparative analysis led to a process wherein categories were developed with each interview, and refined with coding of subsequent interviews. As I would return to the interviews, comparing early coding schema, I scrutinized my decisions, looking for overlap and redundancy. As new data were analyzed, some categories were being merged simultaneously. Overtime categories became more streamlined and there were

fewer new pieces of data. By the end of data collection, after analyzing the last interview, no new categories had been assigned. Strauss and Corbin (1998) suggest that even as a researcher returns to previously completed data analysis, potential exists for new insight to occur, a new naming of a construct, for example. They suggest alternatively that saturation be considered a relative concept with data collection concluding when new information is not adding to the research aims.

The interviews from this study provided depth and breadth, thereby yielding rich data. Descriptive redundancy was achieved with the small sample of 14, which could have been influenced by the nature of using an interview guide and keeping the questions somewhat focused. In spite of using a set of open questions, however, the direction of the conversation was largely directed by the participant, and yet redundancy was achieved with 14 interviews. It may be argued that a larger, similar sample of English-speaking Hispanic/Latinos with CRP would uncover new themes or add greater diversity. While small, the number of interviews and the scope of content met the aims of this study by providing a preliminary descriptive and thematic analysis of participants' experience of CRP.

Triangulation of multiple data sources provided greater context for locating participants' experience in light of the modest sample size (Richardson, 2003). These additional informants and data sources were integrated into analysis. Including other sources of data is another aspect of sampling that informs the individual experience, however, in this study these resources proved to be quite limited. Additionally, medical record documentation of pain served as further data to inform individual experience.

As previously stated, the study design originally included a second participant interview, reflecting and validating the interim findings and soliciting additional data that may not have been originally shared. While this became impossible, the literature on Hispanic/Latino health, cancer, and CRP also provided sources for triangulation and a context to assess the resonance of this study's findings. Themes and categories relevant to Hispanic Latino culture arose in these data that are consistent with themes and descriptions noted in the literature. To address issues of trustworthiness, as themes evolved with the first several participants, these themes then became part of the conclusions in subsequent interviews as a way to perform member checking – see Table 12 (Bowen, 2010). To examine validity, alignment tables were made for each of the three themes – *Pain Is More Than Physical, Ways People Cope,* and *Hurdles and Hindrances* (Tables 22-24). Each provides a summary of how thematic categories are defined and where findings from this study are supported in the literature. Recognizing the limitations in sample size and the diversity of additional informants, I believe this alignment supports validity of the findings.

A potential design for future study could include focus groups of individuals meeting the study criteria but with the intent to validate findings from primary participant interviews and to identify gaps or additional themes. Controversy relevant to this method of validation exists (Madriz, 2003).

I intentionally did not factor acculturation into the study design; the rationale is provided in Chapter III. Some have suggested that acculturation is associated with coping with pain and may be something to consider in future studies as coping became a

significant theme from these interviews (Campbell et al., 2009). Using acculturation as a measure would be more meaningful if Spanish-speaking participants were included.

A final reflection from one interview is shared here that speaks to the challenges I encountered recruiting participants. It took a considerable length of time – 1 ½ years - to collect the sample for this study in a state where Hispanic/Latinos outnumber non-Hispanic white residents (47% vs. 40%, respectively) (US Census Bureau, 2014). While not directly a limitation in this study, it could be in future funded and time-limited studies. As my last interview drew to a close I asked Edgar, the gentleman with a primary liver cancer and his partner of many years to talk about possible reasons it was difficult to find people to talk about their pain.

> *EDGAR**:** I think because it's a cultural thing and they don't wanna, they don't…*
> *PARTNER: They don't admit they're in pain. I think in our culture, it's a cultural thing, yes. We [are] very silent sufferers for whatever crazy reason. And I'm talking about Hispanic women.*
> *EDGAR: And men too. Yea, they're not going to tell you'all, "I'm in pain."*
> *PARTNER: I think most; well I'm just going to speak for myself as a woman. We, we tolerate pain and we don't say we're in pain and I think that's a big time cultural thing. We won't admit that we're in pain because we think we're supposed to deal with it. So maybe that's why you had trouble finding people.*

Final Reflections, Recommendations and Dissemination

Opinions, biases and perceptions about care and healing are conscious and unconscious, culturally shaped by both patient and providers. We must look carefully at our own positionality, patterns of beliefs as individuals and within a framework of care that places providers in the center (Charon, 2011; Mead & Bower, 2000; Mead et al.,

2013). The hope is that assumptions about what we perceive as real or the truth can be called to question, creating the possibility of new understanding and engagement; that what we see as commonplace, ordinary or natural is positioned as such because of its dominance over other positions (Foucault, 1994; Jorgensen & Phillips, 2001). Social structures, processes and providers powerfully shape events, even unknowingly as these norms become internalized within the culture of profession. Many of our practices are unconscious and located within the social norms of conventional healthcare practices. Holding a position of dominance and power may serve to obfuscate the full implications of these practices. Power might be considered "as the ability to define and direct, as the freedom to choose…and is employed and exercised through a net-like organization" (Foucault, 1980). In considering future studies, perhaps the lens of culture and cancer-related pain needs to shift, expanding beyond ethnicity and considering the *culture of pain* from a broader context that includes the multiplicity of factors that converge; providers, patients, systems and communities that as a collective, influence pain care.

Examination of pain guidelines, while well-meaning and evidence-based, may be vacuous and have limited cultural applicability. I suggest that findings from this study and others speak to unrelenting neglected domains germane to Hispanic/Latinos. Remembering the multiple variables that impact experience, how experience is expressed depending on who is listening, and possibly cultural assimilation, we must avoid stereotyping or constructing a singular frozen view of a largely diverse ethnic group.

It may be that in comparing these findings to those of other persons with CRP, that we soon recognize common themes across ethnic groups. In fact Beck and

colleagues (2009) reported themes that resonate with the current study. In their qualitative exploration of satisfaction with cancer pain management, the population was largely not ethnically diverse yet the gaps and desires in pain care reported by the participants overlapped with many found in this study.

In this and other studies, participants spoke of deficits in communication with providers, weakness in full exploration of the pain experience (pain assessment and meaning) and gaps in basic human compassion (Beck et al., 2009; Luckett et al., 2013). Healthcare providers and institutions must examine how power is manifest and what structural influences contribute to unequal positions. It is in this way that a fuller understanding of experience may be understood.

Communication was one category that developed as part of both study aims. Relationship mattered and developing trust was tethered to greater willingness to follow treatment recommendations. Some participants expressed a risk related to speaking up. The consequence of expressing frustration or struggles with the adequacy of pain care could lead to judgment or labeling. Multiple interviews danced around the need to carefully navigate the power differential and the position held as patient, keeping in mind how these factors might impact their pain care. There was not a single example from the data exempt from some degree of resistance or a communication hurdle along the way. It is quite simple; they suggested that providers: "*Get a little more personal….care a little more. Ask: 'How is your pain making you feel? Are you depressed?' …have a little more feelings*."

The decades-long discourse of undertreatment of cancer pain, the important

relevance of cultural diversity to treating pain (as well as cancer), and the multiple sources of data that reinforce these deficits call for an ethical imperative to try new approaches. I do not suggest that the well-respected professional guidelines are not important factors in advancing pain care, but rather, they are not sufficient. Can we look more carefully at authority and how it continues to occupy a significant position in the discourse of pain? Moving forward is more than simply suggesting that we communicate better with our patients, include family, and develop cultural sensitivity – in other words, reciting the same recommendations that have been in place for decades. Change has to begin by recognizing that there is an imbalance of power and position with each patient encounter.

Each interview was the cause of our first encounter, conducted either in homes or clinic consultation rooms. The framework for the interviews was quite different from the many times I have consulted with people of diverse cultures about pain, attempting to conduct a pain assessment and provide recommendations. What was different about the style of these encounters was that I was no longer at the center, controlling the direction of the exchange. For this study, the interview was patient-centric, framed to understand their experiences and how that might better inform approaches to care. I remain confident that the salient temporal ingredients obtained from a complete pain assessment can be achieved when we move out of the center. There was texture, meaning and context provided in these interviews that might have otherwise been absent.

Shifting the paradigm that truly embraces a patient-centered framework as described by Mead and Bower (2000) requires first that healthcare providers pay

attention, acknowledging their position, and recognizing that imbalances and biases can disempower and marginalize others. These realities of such disparities are already well described and experienced among Hispanic/Latino populations and others. Many of these incongruences are not unique to only one ethnic group but underscored by many people with CRP.

In considering ways to modify current provider-centric practice that incorporates the dimensionality of pain care largely consistent with this study findings, Mead and Bower (2000) have developed a framework with five dimensions of patient-centered care. These categories were used by Luckett and others (2013) to situate themes examining barriers and facilitators to cancer pain assessment and management. Mead and Bower's model does not capture all the elements that were identified in this study. For example, missing in this patient-centered model are the caregivers' role in support and advocacy, and the challenges when transitioning between care settings. Their model does provide a framework that fits with many of the analytic findings and may be a good starting place. Domains include:

1. *Biopsychological:* Providers assume the whole person needs will be addressed rather than merely biomedical needs.
2. *Patient as Person*: Affective, cultural, economic, and other factors are recognized as part of care.
3. *Sharing Power and Responsibility*: Enactment of an egalitarian relationship with patients where persons are empowered.
4. *Therapeutic Alliance:* Shared decision-making.

5. *Doctor as Person*: Values the presence of self-awareness, bias, and reflection.

One of the medical providers interviewed in this study recounted how he expressively and empathetically dialogues about pain, using a patient-centric framework. His process begins by asking patients to talk about their pain, interjecting empathic reactions and feedback into the dialogue, encouraging a fuller disclosure of their experience: *"So, I start talking and then I let them lead me and then ask about things as they bring them up."* His style of engagement embodies the principle of narrative medicine or practice – care that is fortified by the knowledge of what to do with stories (Charon, 2011).

I would suggest a coalescence of findings from this study and others that culminate with a few tangible recommendations (Glare et al., 2014; Luckett et al., 2013; Mead et al., 2013). These recommendations are based first on the assumption that the system and providers recognize their shared role in the described disparities and gaps in care. Expanding our understanding hopefully leads to true change in practice. Table 25 outlines recommendations based on the findings from this study which have been recently echoed by others (Kwon, 2014; NCCN, 2014; Paice & Ferrell, 2011). The table proposes actions as they align with the research questions, themes, and associated categories within the themes and are primarily aimed toward changes by healthcare providers and institutions. Many of these recommendations can be operationalized through education, training, and policy.

Evidence continues to associate healthy respectful interaction with providers with outcomes such as quality of life, satisfaction with care, more complete assessments of

Table 25

Summary of Recommendations and Alignment with Study Aims and Themes

Thematic Categories and Research Question (RQ)	Recommendations
- *Being Treated Respectfully* (RQ2) • Being believed, listened to - *Building Relationship and Trust* (RQ1) - *Communication* (RQ2) - *Sources of Support* (RQ1) • Centrality of family	- Neutralize provider-centric encounters, balancing power - Value the narrative and story - Position patient and family/caregiver as authority - Engage patients and family in co-creating pain care plans
- *Building Relationship and Trust* (RQ1) - *Being Treated With Respect* (RQ2) - *Whole Person Experience* (RQ1)	- Explore meaning of pain in clinical encounters of all kinds (specialty care and primary care)
- *Whole Person Experience* (RQ1) - *Description of Pain* (RQ1) - *Understanding of Medications and Side Effects* (RQ2)	- Tailored, individualized assessment - Inclusive of function, affective and social domains - Assess understanding of medications and barriers to use
- *Personal Strategies* (RQ1) - *Culture – Learned Expectations* (RQ1)	- Incorporate inquiry of learned strategies that may come from cultural practices/behaviors
- *Accountability* **(RQ2)** - Positions pain in alignment with other care priorities	- Develop effective methods of communicating between providers as it relates to pain care plans and accountability for care

pain, and surmounting misconceptions and barriers to good pain care, decision-making, and distress (Luckett et al., 2013; Meeker et al., 2011). Conversely, when therapeutic alignment is lacking between provider and patients, mistrust can undermine communication about the pain, resulting in under-reporting of pain by the patient and undertreatment of pain by the provider (Luckett et al.). Clearly after all these years, it is time for the story to change, for care to reflect greater yield and certainly satisfaction on all accounts.

Incentives for placing pain care in tandem with treating cancer need to be illuminated. Newcomer (2012) posits opportunities to balance reimbursement structures in a way that examines patient outcomes instead of solely rewarding providers for prescribing costly drugs. When 70% of revenue comes from products released in the last 10 years to treat cancer, there is little motivation to prioritize time and expertise on symptoms such as CRP. Evidence of this lack of priority was demonstrated through interview and medical record analysis. In the same way that evidence of pain assessment and treatment was difficult to locate during chart abstraction, evidence for cancer treatment was easily found. Newcomer sums up the needed shift:

> Payors and policy experts should carefully align any new payment system with the desired outcomes for cancer patients and society with the goal of achieving the best possible outcomes for the least cost. (Newcomer, 2012, p. 785)

There are implications for institutional change through greater advocacy at the local and state level. Particularly in New Mexico with the focus on the epidemic of prescriptive drug overdoses, those with CRP are potentially at risk for further

undertreatment. Reporting findings of this study as they are situated with the evolving discourse of cancer pain in the country, to local stakeholders, including patient advocacy groups, would be a valuable next step for activating change.

Finally, educators and policy makers need to be made aware of these findings. These themes reveal the persistent nature of gaps in pain care that are uniquely culturally-embedded but also describe universal elements common to the larger population of persons struggling to navigate CRP. Policy, education, practice, and research must continue to pursue efforts to make a difference in the quality of pain care. It will take a concerted effort on all fronts to make this happen. While it remains unknown what will emerge from such diffusion, it is my hope that momentum from these findings may ignite future collaborations within communities that serve Hispanic/Latinos and others with CRP.

APPENDIX A

PARTICIPANT DEMOGRAPHIC DATA COLLECTION

Demographics	**Coding Schema**
Ethnicity	1 = Hispanic or Latino (any race)
Ethnic Heritage	1 = Mexican 2=Puerto Rican 3=Cuban 4 = Other Hispanic or Latino
Years in U.S.	1 = U.S. Born 2 = If born in another country, code as actual # of years in U.S.
Primary Language at Home	1 = Bilingual (Spanish/English) 2 = Spanish 3 = English
Religion	1 = Catholic 2 = Protestant/Christian 3 = Other 4 = No Preference
Gender	1= Female 2= Male
Age in years	Code in years
Marital Status	1 = Widow/Widower 2 = Single 3 = Married
Number of Persons Living in Home	
Annual Family Income	
Working Status	1 = Unemployed 2 = Illness Related Work Leave 3 = On Disability 4 = Working Part-time 5 = Working Full-time
Education Level	1 = < HS 2 = HS Graduate/GRE 3 = Some College 4 = College Graduate 5 = Graduate School
Insurance Status	1 = Not Insured 2 = State Insurance/Salud/Medicaid 3= Medicare 4= Private Insurance

APPENDIX B

IRB WAIVER OF WRITTEN REQUEST

UNM HEALTH SCIENCES CENTER

Human Research Review Committee
Human Research Protections Office

May 12, 2014

Andra Davis

andavis@salud.unm.edu

Dear Dr. Andra Davis:

On 5/12/2014, the HRRC reviewed the following submission:

Type of Review:	Reportable New Information
Title of Submission:	Waiver of Written Request for Unexpected Voluntary Interview Participation
Submitted by:	Andra Davis
Submission ID:	RNI00000422
Documents Reviewed:	• RNI submission dated 05-12-14

This HRRC determined that this information is:

Non-compliance that is neither serious nor continuing

It was determined that this information does not increase the overall risk or harm to the subjects.
The use of data that was obtained under these circumstances is approved.
No further action is required.

Should you wish to respond, please submit a written response to the HRRC within 10 business days. Please let us know if you need additional information.

Sincerely,

Mark Holdsworth, PharmD
Executive Chair

cc:

APPENDIX C

CONSENT

The University of New Mexico Health Sciences Center

Consent to Participate in Research

Toward an Expanded Understanding of Cancer-related Pain among Hispanic/Latinos

6/6/2011

Introduction

You are being asked to participate in a research study that is being done by Andra Davis, who is the Principal Investigator from the College of Nursing. This research is studying experience of cancer related pain.

Many people with cancer experience pain sometimes during their illness. You are being asked to participate in this study because the experience of this type of pain as a Hispanic/Latino has not been well described or understood. Many factors contribute to how pain is experienced. Twenty participants are being sought for this study from the University of New Mexico Cancer Research and Treatment Center, UNM Hospital and Hematology Oncology Associates of New Mexico. These participants will be mostly from the Albuquerque and Santa Fe regions.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. I encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask the study investigator.

What will happen if I decide to participate?

If you agree to participate in this study, you will be asked to read and sign this Consent Form. Here is what will happen if you choose to participate:

1. The investigator will review your medical record to collect information about your cancer and pain.

2. An interview will be scheduled at a time and location of your choice. This interview will take approximately 60-90 minutes and will be audio-recorded to be reviewed later. Andra Davis, the interviewer, will ask general questions. The focus of the questions is to hear about your experience with cancer pain.

3. The same interviewer, Andra Davis will schedule a second interview, again at

a time and location of your choice to review the first interview and follow up with any remaining questions or related topics. This interview will also take approximately one hour.

4. It is hoped that both interviews will occur within the span of one month.

5. You may be asked to review the findings within the next six months. If that is the case, you will have the option of agreeing to a third interview. The purpose of that interview is to consider the findings and express your opinion about how accurately the researcher has summarized the experience of cancer pain found in these interviews.

How long will I be in this study?

Participants will be asked to contribute to two separate interviews over the course of approximately a month. The total time required in this study will be a total of approximately 2 ½ hours over the course of a month. If you are invited to participate in an optional third interview to review all the data findings that will occur once all interviews are completed and analyzed. This would not occur for up to six months after your first interviews.

What are the risks or side effects of being in this study?

Every effort will be made to reduce any risk and hardship of participating in this study. Risks to participation could be inconvenience, stress, or emotional upset because of the types of things that are discussed. Sometimes emotions surface when talking about cancer-related pain which might make you uncomfortable. There is always a risk of loss of privacy or confidentiality however several steps are included to limit those risks. All interviews will be conducted in private closed rooms at the treatment facilities. All contact information and recordings will be stored in the researcher's locked private office. During the recording of interviews, the researcher will not use your name to further protect your identity. Any publications with reference to individuals will use pseudonyms to describe the participants; real names will not be used.

For more information about risks, ask the investigator.

What are the benefits to being in this study?

There may or may not be personal benefits from participating in the study. You may feel that having a place to talk about your experience is such a benefit. It is hoped that the information shared and collected by each participant will help broaden our understanding and care for persons with cancer-related pain as well as possibly identify other societal benefits.

What other choices do I have if I do not want to be in this study?

Participation in this study is voluntary so you can choose not to participate. Nothing will change in your care by preferring not to participate. If you decide during the study that it is becoming too difficult to continue, you may of course discontinue at any time without any effects on your care.

How will my information be kept confidential?

Your name and other identifying information will be kept securely in locked files and only available to authorized members of the research team for the duration of the study. Any personal identifying information or records linking that information to study ID numbers or transcripts from the interviews will be destroyed when the study is completed. Information resulting from this study will be published however you will not be identified by name or any other way to reveal your identity in these publications.

The University of New Mexico Health Sciences Center Human Research Review Committee (HRRC) that oversees human subject research and the University of Utah Internal Review Board (IRB) will be permitted to access your records if requested. Your name or any other way to identify you will not be used in any published reports about this study. A copy of this consent form will be given to you and will remain in your medical record.

What are the costs of taking part in this study?

There are no costs to you for participating.

What will happen if I am injured or become sick because I took part in this study?

If you are injured or become sick as a result of this study, UNMHSC will provide you with emergency treatment, at your cost.

No commitment is made by the University of New Mexico Health Sciences Center (UNMHSC)
to provide free medical care or money for injuries to participants in this study.

In the event that you have an injury or illness that is caused by your participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible

for any associated co-payments or deductibles required by your insurance.

It is important for you to tell the investigator immediately if you have been injured or become sick because of taking part in this study. If you have any questions about these issues, or believe that you have been treated carelessly in the study, please contact the Human Research Review Committee (HRRC) at the University of New Mexico Health Sciences Center, Albuquerque, New Mexico 87131, (505) 272-1129 for more information.

Will I be paid for taking part in this study?

There is no compensation for participating in the study however all efforts will be made to conduct the interviews in a manner most convenient for you.

How will I know if you learn something new that may change my mind about participating?

It is not anticipated that new knowledge from these interviews will change your mind about participation.

Can I stop being in the study once I begin?

Yes. Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting your future health care or other services to which you are entitled.

The investigators have the right to end your participation in this study if they determine that you no longer qualify to take part or if it is in your best interest or the study's best interest to stop your participation.

Authorization for Use and Disclosure of Your Protected Health Information (HIPAA)

As part of this study, we will be collecting health information about you and sharing it with others. This information is 'protected' because it is identifiable or 'linked' to you.

Protected Health Information (PHI)

By signing this Consent Document you are allowing the investigator and other authorized personnel to use your protected health information for the purposes of

this study. This information may include: your medical history and documentation of your pain care, including medications and descriptions of your pain.

In addition to researchers and staff at UNMHSI and other groups listed in this form, there is a chance that your health information may be shared (re-disclosed) outside of the research study and no longer be protected by federal privacy laws. Examples of this include disclosures for law enforcement, judicial proceedings, health oversight activities and public health measures.

Right to Withdraw Your Authorization

Your authorization for the use and disclosure of your health information for this study shall not expire unless you cancel this authorization. Your health information will be used as long as it is needed for this study. However, you may withdraw your authorization at any time provided you notify the UNM investigator in writing.

To do this, please send a HIPAA Research Withdrawal Form or letter notifying her of your withdrawal. Send to:

Andra Davis
MSC09-5350
1 University of New Mexico
Albuquerque, New Mexico 87131

Please be aware that the research team will not be required to destroy or retrieve any of your health information that has already been used or shared before your withdrawal is received.

Refusal to Sign

If you choose not to sign this consent form and authorize use of your PHI, you will not be allowed to participate in the research study.

What if I have questions or complaints about this study?

If you have any questions, concerns, or complaints at any time about the research study, Andra Davis, RN, MN will be glad to answer them at (505) 379-0231.

If you would like to speak with someone other than the research team, you may call the Human Research Review Committee (HRRC) at (505) 272-1129. The HRRC is a group of people from UNM and the community who provide

independent oversight of safety and ethical issues related to research involving human subjects.

What are my rights as a research subject?

If you have questions regarding your rights as a research subject, you may call the HRRC at
(505) 272-1129 or visit the HRRC website at http://hsc.unm.edu/som/research/hrrc/

Consent and Authorization

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided. By signing this consent form, you are not waiving any of your legal rights as a research subject.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. A copy of this consent form will be provided to you.

Name of Adult Subject (print)	Signature of Adult Subject	Date

INVESTIGATOR SIGNATURE

I have explained the research to the subject and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Andra Davis

Name of Investigator/ Research Team Member (type or print)

(Signature of Investigator/ Research Team Member) Date

APPENDIX D

PUBLIC NOTICE

AN IMPORTANT STUDY

Understanding Cancer-Related Pain Among Hispanic/Latinos

If you are:

- **Hispanic/Latino**
- Ages 18-80
- **Experience pain related to cancer**
- Can speak English

Please consider participating in this study

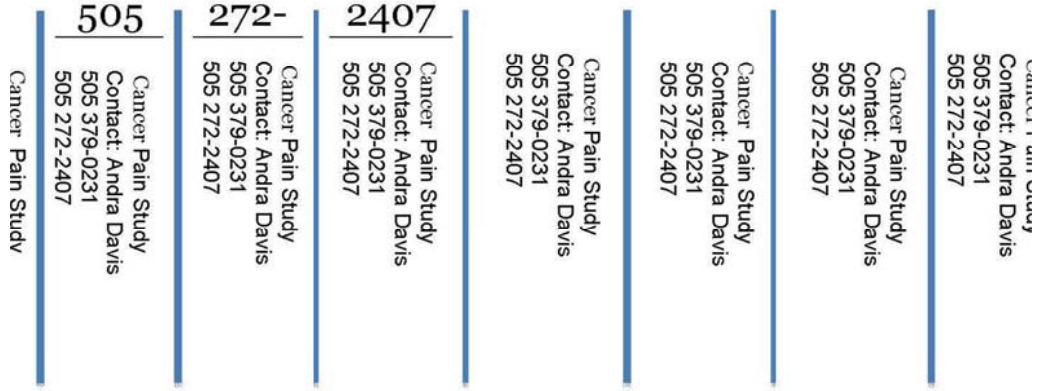
About the study:

- There will be two interviews with one cancer nurse researcher.
- These interviews will be private and can be either in the treatment facility or your home, whatever is easiest for you.

Please contact the researcher for more information

Andra Davis, RN, MN, PhD Candidate
505 379-0231
OR

505 272-2407



APPENDIX E

IRB APPROVAL LETTER

THE UNIVERSITY OF NEW MEXICO
HEALTH SCIENCES CENTER

Human Research Review Committee
MSC 08 4560 BMSB Room B71
1 University of New Mexico--Albuquerque, NM 87131-0001
(505) 272-1129 Facsimile (505) 272-0803
http://hsc.unm.edu/som/research/hrrc/

28-Jun-2011

Davis, Andra,
College of Nursing

SUBJECT: HRRC Approval of New Research Protocol
HRRC#: 11-244
Study Title: Toward an Expanded Understanding of Cancer-Related Pain Among Hispanic/Latinos
Type of Review: Expedited Review
Approval Date: 15-Jun-2011
Expiration Date: 14-Jun-2012

Dear Dr. Davis:

The Human Research Review Committee (HRRC) has reviewed and approved* the above-mentioned research protocol including the following:

1. HRPO Application received 060611
2. Investigator Protocol received 041411
3. UNMHSC combined consent_HIPAA form (participant) v060611
4. UNMHSC consent form (key informant) v041311
5. Recruitment flyers received 041411
6. Data collection form (Medical Record) received 041411
7. Participant Interview Guide received 041411
8. Key Informant Guide received 041411

Consent decision:
Requires a signed consent form
Consent and HIPAA included in same document

If a consent is required, we have attached a date stamped consent that must be used for consenting participants during the above noted approval period.

If HIPAA authorization is required, the HIPAA authorization version noted above should be signed in conjunction with the consent form.

This study is approved to enroll only the number of subjects listed in the application, protocol and consentform(s). the PI wants to enroll additional subjects, it is the responsibility of the PI to submit an Amendment/Change to the HRRC before the approved number of enrolled subjects is exceeded. If increased enrollment is requested, the application, protocol and/or consent form(s) must also be amended to include the new target.

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